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Supporting Complex Needs

A practical guide for support staff working with people with a learning disability who have mental health needs

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Introduction

This document provides guidance on supporting people with a learning disability who have mental health problems. It also provides advice on recognising mental health problems and promoting positive mental health.

People with a learning disability can develop mental health problems just like anyone else. In fact, people with a learning disability are at an increased risk of developing mental health problems compared to those without a learning disability. Many studies have tried to establish the prevalence rate among people with a learning disability, with varying conclusions. This has been due to different populations being studied (e.g. those living in institutions as opposed to those in the community) and the differing criteria used (e.g. some studies include challenging behaviour). After reviewing the literature, Hatton (2002) found that the prevalence rates of mental health problems in people with learning disabilities ranged from 25 to 40 per cent.

People with a learning disability who have mental health problems are often referred to as having a 'dual diagnosis'. To avoid confusion, we have decided not to use this label in this guide as the term is also commonly used to describe the coexistence of mental health and substance misuse problems.

Principles and values of the guide

A clear set of principles and values are at the core of this guide:

- We aim to promote the **rights** of people with a learning disability.
- We recognise people with a learning disability as **equal and valued citizens.**
- We promote the right of individuals to make **choices** and have control over their lives.

Social inclusion is also a key theme throughout the guide. We support the inclusion of people with a learning disability in mainstream mental health services and advocate that people with a learning disability should not be denied access to a service due to their disability.

The guide also promotes the National Service Framework for Mental Health (DOH, 1999) and the Green Light Toolkit as the principal policies for delivering high quality mental health services.

The importance of **partnership working** with individuals, families and a wide range of services is reinforced throughout the guide, giving support staff a clear understanding of their role when working with other agencies.

A **proactive approach** is embedded within the guide, encouraging you to actively promote positive mental health and well-being.

Who is this guide for?

This guide has been developed for staff who provide day-to-day support to adults with a learning disability in a range of care and support settings. This can include either specialist or mainstream services in the voluntary, statutory and private sector, such as supported housing, outreach, day services, employment and in-patient services.

This guide applies to adults of working age, older people and people from black and ethnic minority communities. Some of the information (especially Sections 1, 2, 6 and 7) might be useful for those who support children and adolescents with a learning disability.

Though primarily aimed at support staff, the guide may also be a helpful resource for student nurses and student social workers, family carers and also professionals with little experience of the mental health needs of people with a learning disability.

Why was the guide developed?

People with a learning disability are more vulnerable to developing mental health problems than the rest of the population. However their mental health needs are often unmet because problems may not be recognised, and consequently individuals are not referred to appropriate services for assessment and treatment. Unmet mental health needs have a detrimental effect on a person's quality of life.

The primary aim of this guide is to provide support staff with relevant and accurate information that will enable them to develop the skills to meet the mental health needs of people with a learning disability.

Support staff have a vital role to play in identifying any mental health problems people with a learning disability may develop. However, there is evidence to suggest that they may lack the skills and knowledge to do this. Staff also need to be aware of the range of services and support available and how this can be accessed. This will enable staff to support individuals to seek help, to attend appointments, etc, and to act as advocates on their behalf.

Support staff can make a valuable contribution to the assessment process, providing a wealth of information and supporting the individual through a potentially stressful and difficult experience. There are a number of different interventions available and it is likely that support staff will also be involved in these. By working through this guide the reader should develop a greater understanding of:

- What constitutes a 'learning disability', 'mental health' and 'mental health problems'.
- Why people with a learning disability may be vulnerable to developing mental health problems.
- How mental health problems can present in people with a learning disability.
- The range of service provision to meet the mental health needs of people with a learning disability.
- The roles and responsibilities of support staff and

health and social care professionals in meeting mental health needs.
- Effective communication and collaboration with different professionals and services.
- The assessment process and the range of interventions to support those with mental health problems.
- Promoting the inclusion of people with a learning disability in mainstream mental health services.

The guide has been devised to support the development of a skilled and competent workforce, who will work in partnership with people with a learning disability to ensure that their mental health needs are met. The guide aims to help support staff to develop their range of skills and knowledge and has therefore been aligned to the 'mental ill health' units in the new joint Learning Disability Awards Framework (LDAF)/National Vocational Qualification (NVQ). The new joint award will allow staff to obtain the underpinning knowledge, together with practice-based learning, through a single process. This process also matches the new National Minimum Data Set for Social Care (NMDS).

How was the guide developed?

Support staff in a range of care settings and people with a learning disability were involved in developing this guide.

- Care and support staff who work with people with a learning disability and mental health problems were interviewed during the initial stages of development. They were asked a range of questions

about the information that would be useful for staff to receive prior to starting their employment; about what was helpful and what the obstacles were in providing effective care; and what they thought should be included in the guide.
- People with a learning disability were also interviewed about how staff could better support those with mental health problems.

The information from these interviews has shaped the final document. Throughout the document you will find quotes from people with a learning disability who use services.

A steering group has overseen the toolkit development. The group included people with learning disabilities, support staff, managers, clinical staff and policy makers. The group helped develop the layout of the toolkit and advised on its contents.

How to use the guide

This is a practical guide which offers a basic introduction to the mental health needs of people with a learning disability. It is also a reference source, providing you with resources to obtain further information on learning disability, mental health and associated issues.

The guide has been designed so that you can easily locate particular information when needed. Following this introduction, the rest of the guide is divided into three parts for ease of use:

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Part A: Understanding learning disability and mental health

Section 1 gives an introduction to mental health problems. It defines learning disability, mental health and mental health problems. It discusses how mental health problems can affect people with a learning disability. An overview of the main types of mental health problems and how they are recognised in people with a learning disability is provided. The differences between challenging behaviour and mental health problems are also discussed.

Section 2 explores the factors that can make people with a learning disability vulnerable to developing mental health problems. It discusses social, psychological, emotional and physical factors.

Section 3 looks at the key policies that have shaped and are shaping mental health services for people with a learning disability, such as Valuing People (DOH, 2001) and the National Service Framework for Mental Health (DOH, 1999). Key legislation that affects people with a learning disability and support staff is described, notably the Mental Capacity Act (2005) and the Mental Health Act.

Part B: Supporting people and getting help from services

Section 4 explores how positive mental health can be promoted. It describes the proactive strategies that you can put in place to reduce the likelihood of mental health problems occurring. It also provides information on how to support people in times of emotional distress.

Section 5 discusses how the signs of mental health problems can be recognised and how staff can help people with a learning disability to access support. It describes the key services that are available to people experiencing mental health problems and how these services interact with each other and the professionals who work within these services. It also provides ideas on how you can work in collaboration with health and social care services, including an example case study.

Section 6 gives an overview of the assessment process and explores how staff can support people with a learning disability through mental health assessments and how they can contribute to the process. It also describes how a diagnosis may be reached.

Section 7 looks at the main types of interventions and treatments that are available to people with a learning disability who have mental health problems. The role of support staff in implementing interventions is described.

Part C: Good practice summary and further information

Section 8 gives a summary of good practice recommendations.

Section 9 is a comprehensive resource for obtaining further information. It provides references for further reading; materials to help support people with a learning disability with their mental health; and addresses and websites for organisations that can help.

The appendix provides an overview of the main types of prescribed medication for mental health problems.

We hope this guide will be useful to you and help you in delivering high quality care to people with a learning disability and meeting their mental health needs.

Part A:
Understanding learning disability and mental health

Section 1: People with a learning disability and mental health problems

1.1 How can I tell if someone has a learning disability?

It is not always easy to tell if someone has a learning disability. Some conditions such as Down's syndrome have physical characteristics, but often this is not the case. The simple answer is that you may not necessarily know. The degree of learning disability and presence of other disabilities will vary from person to person. What is important is to be open minded and be willing to give appropriate support where needed.

1.2 What is a learning disability?

The term 'learning disability' refers to a large group of people who have a wide range of different abilities and needs. A learning disability is a lifelong condition, which affects about 1.5 million people (2 per cent of the population) in the United Kingdom (DOH, 2001).

A learning disability is not the same as a mental health problem. People develop mental health problems throughout their lives and many people with mental health problems can overcome these problems over time and with support. A learning disability is not an illness and cannot be 'cured'. Learning disability is often present from the early stages in a person's life, generally occurring at conception, during pregnancy, at birth or shortly after birth. There are many possible causes of learning disability, including infections or accidents during pregnancy, complications at birth and trauma in infancy. Learning disability is also sometimes associated with different types of syndromes, which are caused by genetic factors. The most commonly associated syndromes are Down's syndrome and Fragile X syndrome.

A learning disability affects a person's level of intellectual and cognitive functioning and sometimes their physical development. A person with a learning disability may have greater than average difficulty in learning new skills, or in coping independently. They may learn at a slower pace and sometimes find it difficult to carry out tasks such as using money, reading and writing. Just like everyone else, people with a learning disability have different skills and abilities. With appropriate support, tailored to build on their strengths and address their needs, people with a learning disability will have the opportunity to develop skills.

The 'medical' model of disability describes different levels of learning disability as mild, moderate, or severe and profound.

The majority of people with a **mild learning disability** live independently; many have their own families, are in employment and have no need for extra support from services, except in times of crisis.

For people with a **moderate learning disability**, the level of support needed is higher. Many people will need some degree of support with everyday tasks and may have difficulty in communicating their needs. They are likely to use a number of support services such as day, outreach and supported living schemes. It is estimated that there are 1.2 million people with mild to moderate learning disabilities (DOH, 2001).

People with **severe and profound learning disability** have significantly increased health risks such as higher rates of epilepsy, sensory impairments and physical disabilities. They are likely to have more complex needs and greater difficulty in communicating their needs. Sometimes individuals engage in behaviour that others consider challenging, in an effort to communicate their need or as an expression of their frustration. Self-injurious behaviour is more common in people with profound learning disability. In severe cases this can lead to additional disability, poor health and a significantly decreased quality of life.

People with severe and profound learning disability can also be described as 'people with high support needs'. This more contemporary language is being used by many people and organisations and is now included in government policies.

The number of people with a learning disability in the UK is expected to increase over the next few decades, by approximately 1 per cent every year (DOH, 2001). This is due to several factors:

- Improved life expectancy will result in a 37 per cent increase in the number of people with a learning disability aged over sixty by the year 2021 (Emerson and Hatton, 2004).
- The maternal age of women is increasing, resulting in higher risk factors for some conditions associated with learning disability, such as Down's syndrome.
- Over the last 50 years the UK has become a multicultural society. Some ethnic minority groups, particularly those of South Asian origin, have a higher prevalence of births of children with a learning disability, especially severe learning disability (DOH, 2001).

1.3 What is mental health?

Mental health is as important as physical health. Good mental health helps people cope with day-to-day living, major life-changing events and decisions. The Health Education Authority (1997) defines mental health as:

> 'the emotional and spiritual resilience, which enables us to enjoy life and to survive pain, disappointment and sadness. It is a positive sense of well-being and an underlying belief in our own and others' dignity and worth'

Mental health includes more than just a person's state of mind – it is central to well-being. It includes medical and social factors. Mental health is not just an absence of illness, but is a state of wellbeing. Our mental health affects the way we view the world, interpret events and communicate with those around us.

Everyone has mental health needs. When these go unmet, the person is likely to develop mental health problems. It is essential that all those who support people with a learning disability recognise the importance of good mental health and the impact it has on overall well-being and quality of life.

1.4 What is a mental health problem?

Sometimes a person's ability to cope with day-to-day life is put under great strain. They may not be able to function as they usually would. When this happens we say that the person has a mental health problem. There is a wide range of mental health problems. Symptoms can vary dramatically in severity and intensity. For example, one individual with a learning disability may develop mild depression following a bereavement, and experience feelings of sadness and low mood, but may still continue their usual activities, possibly with less pleasure. In contrast, another person suffering a bereavement may have great difficulty in functioning, becoming withdrawn, not eating or sleeping and may need extra care and support for a period of time.

People with mental health problems experience significant changes in the way they **think**, their **emotions** and the way they **behave**. The following are general examples of how a mental health problem can affect people.

Examples of effects of mental health problems

Changes in thinking: Some people may hold unusual beliefs, be preoccupied with negative thoughts or have difficulty in concentrating. Thought processes may be slowed down or speeded up.

Emotions: Changes in mood, for example feeling low, sad, elated or irritable, all or most of the time.

Changes in behaviour: Such as loss of interest in activities and relationships, isolating oneself, not looking after personal hygiene or appearance, being restless or overactive.

These changes impact on the way the person functions on a daily basis. Each type of mental health problem will have specific associated changes and these are discussed towards the end of this section.

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1.5 Why are people with a learning disability more likely to develop mental health problems?

Mental health problems are common, affecting one in six adults at any one time (ONS, 2000). People with a learning disability can develop the full range of mental health problems. Research suggests that there is an increased likelihood of people with a learning disability developing a mental health problem, with figures ranging from 25 to 40 per cent (Hatton, 2002). This could be due to those with a learning disability being more vulnerable to factors that can predispose people to mental health problems (these factors are described in detail in Section 2).

1.6 Incidence of particular mental health problems

- Schizophrenia has a prevalence of 3 per cent in people with a learning disability. This is three times higher than those without a learning disability (O'Hara and Sperlinger, 1997).
- Between 1.3 and 3.7 per cent of people with a learning disability will have depression at any one time. This is twice as high as for the general population (Deb et al., 2001).
- Generalised anxiety disorder is equally common, and according to some studies more common, among people with learning disabilities (Raghavan, 1997).
- The prevalence of dementia for people with Down's syndrome is significantly increased, with prevalence

rates of 9 per cent for ages 40–49, 36 per cent for ages 50–59 and 55 per cent for people aged 60–69 (Alzheimer's Society, 2000).
- There are higher rates of bipolar disorder in people with a learning disability (Dosen and Day, 2001).

These and other different types of mental health problem will be fully described below.

1.7 Recognising mental health problems in people with a learning disability

When a person develops a mental health problem they experience changes in their thoughts, behaviours and feelings and these may affect their physical health. These changes are called **signs** and **symptoms**.

- A **sign** of a mental health problem is something that other people can see and is usually a change in behaviour, for example when someone does not take care of their personal appearance as they normally would.
- A **symptom** of a mental health problem is an internal experience, such as when a person has unusual thoughts or beliefs (e.g. 'people are out to get me') or feelings of despair.

Symptoms and signs can be due to mental health problems. However, they can also result from physical conditions such as thyroid problems or urinary tract infections (see Section 4).

It is particularly important to be alert to changes in a person's thoughts, behaviours or feelings. Changes suggest something different is happening to the individual, and that may be a physical or a mental health problem. For example, Person A does not care much about her appearance, is shy, enjoys her own company and has a very limited set of interests. These are normal characteristics for Person A, but if Person B started behaving in this way, it could be unusual and might suggest the possibility of a mental health problem or physical ill health.

Areas that change when a person develops a mental health problem include:
- physical state, such as increase or decrease in appetite, weight or sexual desire; stomach upsets, headaches
- levels of energy and activity
- high, low or irritable mood
- odd, unusual beliefs, which are out of character
- problems with memory and concentration
- a reduced ability to adapt to new situations or learn new skills
- challenging behaviour
- personal relationships and levels of social interaction
- physical appearance and hygiene
- communication patterns.

For tips on what to do when a mental health problem is noticed, see *Part B: Supporting people and getting help from services.*

The impact of mental health problems on the person's quality of life is discussed at the end of this section.

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1.8 What are the different types of mental health problems?

Schizophrenia

Schizophrenia is a diagnosis given to people who have disrupted beliefs and experiences. There are different types of schizophrenia and not everyone has the same symptoms. Schizophrenia is known as a psychotic illness, meaning that the person's view of the world does not match reality. For instance, they may have unusual and false beliefs (delusions) or see or experience things that are not there (hallucinations) and act in unusual ways as a result.

The causes of schizophrenia are unknown but it can be found more commonly within families, suggesting a genetic link, and it appears to be associated with changes in brain chemicals. Schizophrenia generally develops when people are in their late teens or early twenties and can be triggered by a combination of factors, including stressful life events.

About one in 100 people without a learning disability will experience schizophrenia during their lifetime and two thirds of these will go on to have further episodes and require ongoing support and treatment (Zenman, 1997). Schizophrenia is three times more common in people with a learning disability than in the general population (O'Hara and Sperlinger, 1997). The diagnosis is largely based on the person being able to explain their internal experiences such as delusions and hallucinations, and so is rarely made in those with a more severe learning disability.

The signs and symptoms of schizophrenia are split into two groups – 'positive' and 'negative'. Positive symptoms refer to abnormal experiences and include delusions, hallucinations and unusual behaviours related to them. Negative symptoms are more long-term, and include some loss of normal experience, for instance apathy and social withdrawal.

Positive symptoms

Delusions

Delusions are false beliefs that are not grounded in experience and that other people do not share. Even when provided with solid evidence to the contrary, the belief in the delusions remains. When considering whether a belief is a delusion or not, it is vital to bear in mind the person's background. For instance, a belief might be appropriate for someone's developmental level but be unusual for someone without a learning disability of the same age (e.g. having an imaginary friend). Their beliefs may be appropriate for their culture but seem strange to people not from that culture (in which case the belief would be seen as a shared cultural belief and not a delusion). Also, the person's cultural beliefs may be reflected in their delusions. For example, certain foods may be particularly valued in a culture. An individual may believe that eating that food is especially good for them (cultural belief) and that it will give them super-human strength (delusion).

Positive symptoms tend to occur during acute episodes and can be very frightening. They can be of a persecutory nature, such as a person who believes the staff or a member of their family is 'after them' or giving them poison instead of medication. Some people have grandiose delusions, where they believe themselves to be of extreme importance, such as being a messenger from God. People can also believe that their thoughts and actions are controlled by others or that their conversations are being recorded.

People with a learning disability who have schizophrenia may experience delusions. These can be difficult to assess if the person is not able to communicate their experiences effectively. For example, a man may tell the support staff that 'they are all out to get me'. He appears very paranoid and confused and cannot elaborate. This could be interpreted as psychotic symptoms but in reality he may have been bullied but be unable to communicate this.

Hallucinations

Hallucinations are experiences that occur without the presence of something actually causing them, i.e. hearing, smelling, seeing, tasting or feeling things that are not there.

The most common hallucinations involve hearing voices (auditory hallucinations). To the person with schizophrenia, the voices appear to come from an external source rather than from their mind. They may appear so loud that the person believes that other people will also be able to hear them. The voices may say negative things to or about the person. With some individuals, the voice(s) order them to do things.

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People with learning disability who have schizophrenia are likely to experience hallucinations that are in line with their communication and developmental abilities, so they may be expressed in broad terms without details e.g. 'I hear clicks' or 'I hear voices' (without being able to explain further).

The impact of positive symptoms

These positive symptoms outlined above can be very distressing for the individual. It is important to remember that delusions and hallucinations are very real to the person. Though others may know these to be untrue, this does not lessen the fear or distress that the person is experiencing.

People who experience positive symptoms are likely to show changes in their behaviour. They might become upset, anxious, confused or suspicious of other people. They may also be reluctant to believe that they need help.

Negative symptoms

Negative symptoms are when a person experiences a degree of withdrawal from their daily life. They include decreased motivation and energy, lack of initiative, slow movements, reduced communication (both verbal and non-verbal), loss of interest in relationships and activities and self-neglect. Negative symptoms are less dramatic then positive symptoms but tend to be more persistent. People with negative symptoms often appear preoccupied with their inner world. In some cases a person may become more isolated or depressed because of other people's response to their behaviour, rather than their symptoms being part of the schizophrenic illness itself.

Depression

Depression is the most common mental health problem; roughly one in five people experience depression over the course of their lives and one in twenty experience more severe symptoms (Borrill, 2000). Its length and severity varies widely from a short-term reaction to an adverse event to a prolonged episode that interferes with the ability to function, feel pleasure or maintain interest in activities. People face a number of major events throughout life, such as bereavement, leaving school, moving home. These can lead to feelings of depression and low mood. Sometimes these feelings arise for no obvious reason. Such feelings normally subside over time, as coping strategies are developed. However, for some, the feelings of depression may be more severe and may continue, starting to affect the person's everyday functioning and quality of life. It is at this point that the person might be considered to have clinical depression and need some form of intervention.

Depression affects people in different ways. They may have physical, emotional and psychological symptoms. The key features are feelings of sadness, helplessness and hopelessness accompanied by a loss of energy and interest in activities, aches and pains and sleeplessness. At its worst people may lose the will to live or consider suicide.

A person with a learning disability may not be able to communicate their feelings easily in words. Some people may not realise they are depressed especially if they have been feeling that way for a long time. Staff, through observation and accurate record keeping, may be alerted to changes of mood or behaviour that may be signs of depression.

Manic depression (often called bipolar disorder)

Manic depression (also known as bipolar disorder) is characterised by extreme changes in mood, thought, energy and behaviour. A person may alternate between an elated (high) mood, known as mania, and a low, depressed mood.

In mania the person has an overwhelming feeling of elation, without reason. It may be difficult to detect in the early stages, as the person can appear to be simply very excited and happy. They may have grandiose ideas or wild plans, lose insight and experience delusions. Mild episodes of mania are called 'hypomania', when symptoms cause mild disruption to the person's everyday life. In contrast, with mania there is a profound effect on the person's functioning.

Features of mania:
- high elated mood
- excessive energy resulting in significantly increased activity (though this is usually unproductive)
- extreme irritability and agitation
- decreased sleep (in mania the person may not sleep for days)
- racing thoughts and over-talkativeness

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- being overly familiar, even with complete strangers
- demanding and impulsive behaviour
- lack of concentration and becoming easily distracted
- unrealistic beliefs in special abilities and powers.

Staff can often recognise the changes of mania, as the majority are behavioural and have a significant impact on the interactions between the person, staff, family and other people using the service.

Manic episodes tend to start abruptly and be shorter in duration than depressive episodes. They may be followed by a period of depression. They tend to recur, and the length between episodes varies greatly.

Dementia

Dementia is a progressive disease affecting the brain and is characterised by personality changes and deterioration of skills, behaviour and cognitive functioning. The most common form of dementia is Alzheimer's, which is responsible for over half of all dementias. Most dementias are irreversible with permanent loss of brain tissue and will eventually lead to the person's death. The course of dementia can vary, although indications are that the average time from diagnosis to death is about six years (Emerson et al., 2001).

Key features of dementia include:

Early stages
- loss of short-term memory
- confusion
- difficulty in concentrating and understanding others

- problems in communicating verbally
- symptoms of anxiety and depression
- losing self-help skills such as personal care and domestic skills
- problems with orientating oneself in relation to time and place.

Later stages
- loss of speech
- physical health problems
- immobility
- epileptic seizures
- total loss of skills and dependence on others
- incontinence
- problems with eating and drinking
- mood and personality changes.

People with a learning disability are living longer and as a consequence may develop dementia in later life.

Dementia is more common among people with a learning disability and even more so in those with Down's syndrome. People with Down's syndrome are also more likely to develop dementia at a younger age (Alzheimer's Society, 2000). The initial signs and symptoms of dementia such as poor memory and loss of skills can be difficult to recognise in people with a learning disability, especially in those with severe disabilities. This is also partly because people may be supported by staff or carers, so subtle changes are unnoticed.

Anxiety

Feelings of anxiety are common. Whilst such feelings can be unpleasant, they rarely last long and most people can cope. However, for some people the feelings do not go away and interfere with their daily routine and functioning. They may feel anxious all the time and this anxiety controls their life.

There may be physical symptoms, such as palpitations, rapid breathing, sweating and dry mouth. Sleep may also be disturbed.

There are several types of anxiety disorder and people with a learning disability can develop all of them, including:
- generalised anxiety disorder
- panic disorder
- phobic disorders
- obsessive-compulsive disorder
- post-traumatic stress disorder.

People with anxiety disorders may seek reassurance from and be demanding of those who support them. They may be reluctant to leave those to whom they feel closest. They may lose their temper over minor issues or show unusual behaviours when overwhelmed with feelings of panic, such as sudden collapse (although physically well).

It is also important to note that new situations may trigger feelings of anxiety, which staff may mistake for a phobic reaction, rather than a normal stage of adjustment.

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Personality disorders

We are used to thinking of 'personality' as the characteristics that make us unique. However, the term 'personality disorder' is used when these personal characteristics cause someone to have regular and long-term problems in the way they cope with life and interact with other people. There are different types of personality disorders. The *Diagnostic and Statistical Manual of Mental Disorders*, 4th edition (DSM–IV), identifies ten: paranoid; schizoid; schizotypal; antisocial; borderline; histrionic; narcissistic; dependent; avoidant; obsessive-compulsive. An individual may have more than one type. However, it is likely that some people experiencing these problems will not come into contact with mental health services. Others may easily be misdiagnosed, particularly because the symptoms may be more general than those of other mental disorders. In addition, some people may have other mental health conditions co-existing with personality disorders, but these are not always diagnosed.

In the past, some professionals thought that personality disorders were untreatable. This has led to significant confusion and misunderstanding as well as poor or patchy commissioning of services.

Approximately 10 to 13 per cent of people without a learning disability have a personality disorder (Weissman, 1993).

There is little research in the field of learning disabilities regarding personality disorder, thus the prevalence is uncertain. The few studies that have been carried out have found figures ranging from 22 to 27 per cent, but these should be interpreted with caution due to the difficulties in making the diagnosis in people with learning disabilities (Deb et al., 2001). There is also little understanding of the diagnosis and treatment of people with a learning disability with concurrent personality disorders.

Eating disorders

Eating plays a large part in daily life. Most people have an eating pattern, such as eating at the same times, particular meals on certain days and generally eating the same amount each day. But in times of emotional turmoil or stress these routines can be disrupted and one may eat more or less. Often, once the problem has been resolved, eating behaviour returns to normal. For some people food can become the main focus of their life and can be used as a coping mechanism to deal with ongoing emotional distress. The term 'eating disorder' would apply in these situations.

Eating disorders can affect anyone. They are characterised by severe disturbances in eating patterns and consumption, causing psychological and emotional distress and affecting physical health.

As with all mental health problems the cultural and social background of the individual needs to be considered, for example fasting due to religious beliefs would not be considered an eating disorder. Eating is also affected in other types of mental health problems such as depression.

The main types of eating disorders are:

Anorexia nervosa
This is when an individual deliberately refuses to eat enough food to maintain a normal weight, even though they might be experiencing severe hunger. People often have a distorted body image, continuing to believe they are overweight when this is not the case.

Bulimia
This is when a person eats a greatly increased amount of food within a short period of time and then induces vomiting or takes laxatives/diuretics in order to eliminate the food.

Pica
This is where an individual eats substances that have no nutritional value and are not considered food (e.g. sand, faeces, tissue paper, etc.). Pica is more common among people with severe and profound learning disability.

1.9 Autism

Autism is a developmental disorder that affects an individual's behaviour in three areas:

- social interaction
- communication
- restricted and repetitive behaviours, interests and activities.

Autism is a lifelong condition that is often associated with learning disability. Many people with autism do not have a learning disability and are described as having Asperger's syndrome or high functioning autism.

People with autism are more at risk of developing depression and anxiety disorders. Further information about people with autism can be obtained from the National Autistic Society and their contact details are listed in Section 9.

1.10 What is challenging behaviour?

The term 'challenging behaviour' refers to behaviour that has been adopted or developed to express, communicate or meet individual needs and desires. It often has a negative impact on a person's quality of life or the quality of life of the people with whom they live (Baker, 2002). It can be low-key behaviour such as continuous repetition of words and phrases. It can also encompass behaviour that can cause harm to the person themselves or to others. It may include verbal and physical aggression, self-injury and anti-social behaviours. Up to 15 per cent of people with a learning disability exhibit some form of challenging behaviour (Emerson et al., 2001). Severe challenging behaviour occurs in approximately 6 per cent of people with a learning disability. This is where injury has been caused and/or beahaviour which places the person or others in danger and an intervention is required from staff or carers.

People with a learning disability, especially those with additional sensory and physical disabilities, may have difficulty in communicating with others. This can lead to frustration and the person not having their needs met. In these instances people with a learning disability may use forms of challenging behaviour to communicate their needs. If the person successfully communicates to others using challenging behaviour they are likely to use it again. It is vital that we try to understand why challenging behaviour occurs and work with the individual in developing alternative ways of communicating their needs.

Challenging behaviour has a detrimental effect on the individual. It is likely to limit their access to the community and may lead to them being excluded from services. They may be segregated from others by being placed in 'specialist services' with other people who present with challenging behaviour. People who present with challenging behaviour are also at greater risk of abuse.

As previously mentioned, communication is a major contributory factor to challenging behaviour. However, challenging behaviour has many causes and individuals are likely to engage in challenging behaviour for a variety of reasons.

- The environment impacts on a person's behaviour. For example if a person has little choice, little to do and a lack of positive interaction with other people they may engage in challenging behaviour.
- Challenging behaviour may occur as a reaction to

pain or be associated with epilepsy (before, during or after seizures). Some syndromes (Lesch-Nyhan and Prader-Willi) are particularly associated with challenging behaviour.

- Challenging behaviour may or may not be a sign of a mental health problem. Support staff and health and social care professionals should neither make assumptions that challenging behaviour is due to a mental health problem nor fail to consider the possibility that it could be.

In the past, the approach to challenging behaviour was often to punish the person (i.e. take something away or seclude them).

New approaches to challenging behaviour include trying to find out why the person behaves this way, and then tailoring an intervention appropriately. Examples of interventions directly tailored for challenging behaviour include:

- Supporting people to communicate something that previously they communicated in a challenging way (e.g. learning to use the Makaton sign for 'no' instead of being aggressive so as not to do something they dislike).
- The environment may need to be changed (e.g. by providing a choice of stimulating activities).
- Any physical problems should be addressed (e.g. urinary infection causing pain).
- In some instances the person may be given medication to calm them down. Good practice suggests that this should only be in the short term

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whilst trying to ascertain why the challenging behaviour occurs.

These supports form only part of the approach to challenging behaviour.

As with all people with a learning disability, where an individual's behaviour is considered challenging a person centred approach is vital. This approach can identify what is occurring in the person's life and ensures that staff do not just concentrate on their behaviour. Using a person centred approach means looking at the person as a whole and considering a range of needs, wishes, wants and desires. It is important that you try to fully understand what is important for the individual, strive to improve their quality of life and reduce any behaviours that may be challenging.

1.11 What is the relationship between mental health problems and challenging behaviour?

The relationship between mental health problems and challenging behaviour is complex. Both can exist at the same time and one can be a consequence of the other. A change in behaviour (either in its nature or intensity) is particularly suggestive of a new issue for the person, which could be a mental health problem. For example, in schizophrenia the person may try to remove auditory hallucinations by self-injuring or become aggressive because they feel paranoid about those around them.

Any assessment of challenging behaviour must consider mental health problems as a potential cause.

This publication does not discuss the assessment of challenging behaviour or intervention methods, except when they are part of wider mental health problems. The authority on this subject remains the Mansell Report (DOH, 1992), which is still relevant today. More information on this publication and this topic can be found at the Department of Health and the Challenging Behaviour Foundation respectively (their websites are listed in Section 9).

1.12 Why do mental health problems need to be addressed?

If mental health problems are not recognised, assessed and treated there is a detrimental effect on the person's quality of life. The following are often a reality for people with a learning disability and mental health problems:

- Relationships with staff, family, friends and other individuals can become strained. There is a risk that people can become isolated.
- Their behaviour may jeopardise their places at day services, employment and residential establishments.
- They are less likely to access the same treatment facilities as other local people without a learning disability.
- They are more likely to be placed in 'specialist' units for people with learning disability. These may be a long distance from family and friends.

- They may develop physical health problems, e.g. due to self-neglect, and may try treating themselves by increasing alcohol, drug or cigarette use.
- There may be an overuse of medication and limited use of other treatments, such as psychological interventions.
- People may have less choice and have fewer opportunities to express their views and opinions.

The next section will explore the factors that can make people with a learning disability vulnerable to developing mental health problems.

Section 2: Factors that affect mental health

People develop mental health problems for a variety of reasons. Social, psychological, emotional and physical factors can lead people to develop mental health problems, and people with a learning disability are more likely to encounter some of these factors in their lives. You should consider a range of needs that may affect an individual's mental health and in collaboration with the person develop plans to meet those needs and reduce the person's vulnerability to mental health problems.

2.1 Social and economic factors

Social factors involve our environment and the people in it. They include:

Abuse and exploitation
Abuse, whether it is physical, sexual, emotional or financial, can increase an individual's vulnerability to mental health problems. We know that abuse often goes unreported, and research suggests that it is more prevalent among people with a learning disability. People with a learning disability may be more dependent and over-trusting of others and this could lead to them being exploited by strangers. They may find it harder to protect themselves and may not be able to tell others what has happened. Moreover, people with a learning disability may have difficulty in communicating their experiences and may not be supported through this or given the counselling that they need.

Staff should remain aware of the importance of special programmes that enable the development of sexual expression among young people with a learning disability, while at the same time fostering their capacity for protection from abuse.

Prejudice and discrimination
Stigma is often attached to having a learning disability. Prejudice and discrimination are part of daily life for many people with a learning disability. It can occur in a wide range of situations including employment, access to community facilities and services.

Culture, spirituality and religion
If cultural, spiritual and religious beliefs are ignored, vulnerability to mental health problems can be increased.

Black and minority ethnic communities
People from black and minority ethnic (BME) communities face substantial inequalities, discrimination and disadvantage. This includes poor housing, adverse socio-economic conditions and discrimination in employment, education and health/social care services. As well as facing increased vulnerability to mental health problems due to these factors, people from BME communities with a learning disability also experience further discrimination and vulnerability due to race and disability factors.

Family issues
The families of people with a learning disability often face many challenges, e.g. time taken off work to look after their child or relative. This may have financial implications.

Parents may be fearful of their son/daughter's vulnerability and may become overprotective. For example, when their child reaches early adulthood they may treat him/her as someone much younger. Learning experiences, e.g. around independence and expressing sexuality, may be denied to the individual for fear of possible risks.

People with a learning disability may be dependent on their family well into adulthood and remain under their family's influence for longer. These situations may cause stress, potentially affecting all members of the family.

The environment
The environment influences our mental health. Some people, for example, prefer places that are quiet, whereas others thrive in environments that are very stimulating, with lots of noise and activity. Some environments are more restrictive than others. If the environment does not suit the person's needs it can be stressful for them. People who have lived in or are living in institutions are particularly vulnerable to the nature of the environment.

People who offend
People with learning disabilities who find themselves in trouble with the law are often discriminated against during their contact with the criminal justice system (police station, courts and prison). Their health and social care needs are often overlooked and there is little proactive support to help individuals return to their local communities, undergo rehabilitation or prevent them from reoffending. All of these factors can have a detrimental effect on the person's mental health.

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Financial disadvantage
Some mental health problems are more common among people with low income. People with a learning disability are amongst the most financially disadvantaged people in the country.

Smaller community networks
Having a limited social network, with a lack of support from other people, is a recognised risk factor for mental health problems, especially depression.

Exclusion
People with a learning disability are one of the most excluded groups in our society. This includes living in institutions and not being able to use mainstream services. A recent survey that was commissioned by the government found that people with a learning disability were often excluded, for example living in poor and deprived areas, having poor health, a lack of employment, education and voting opportunities (Emerson et al., 2005).

The following diagram shows how having a mental health problem leads to greater exclusion, which in turn can lead to the person being more vulnerable to developing mental health problems. People with a learning disability are already discriminated against and having an additional mental health problem increases this discrimination.
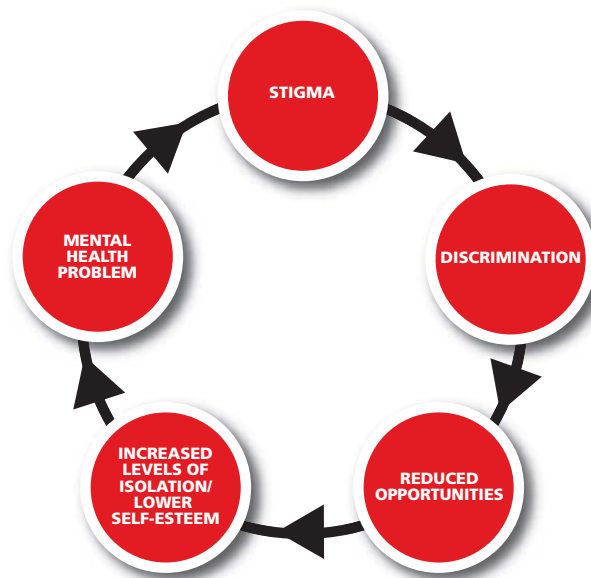
Hardy, Woodward and Barnes (2005)

Expectations of others
The expectations of others also affects people. Often people with a learning disability are expected to fail and as a result are not given chances to learn from new experiences. Conversely, they may be given tasks to do that are too difficult for them, which they cannot achieve. Such experiences may lead to low self-esteem and may lead to the person developing mental health problems.

Transitions and changes
Poorly planned transitions are stressful, and people with a learning disability often have very poorly managed transitions. For example, when they reach adulthood and transfer from children's services, when moving home or in the event of support staff leaving. What may seem trivial to staff may be very stressful for the person with a learning disability, such as a change of day centre or college activities not continuing outside of term-time, etc. It is important, where possible, for care staff to plan all transitions collaboratively and allow greater adjustment time and increased support as necessary.

2.2 Psychological and emotional factors

Psychological and emotional factors are concerned with thoughts, feelings and emotional reactions. They include:

Poor self-esteem
Society tends to value certain achievements such as having a job, owning a house and having children. People with a learning disability may feel that they are not as good as others because they may have difficulty in achieving these things. They may find it difficult to cope with the stresses that arise day-to-day and to understand and solve problems. These difficulties may lead to low self-esteem.

Negative learning experiences
People with a learning disability often have a lifetime of negative learning experiences, which can increase vulnerability to mental health problems. They may have been denied valuable learning experiences because it

was assumed that they would fail or that it was too risky to put them into certain situations. This is especially true for those who have previously lived in long-stay institutions. People with a learning disability may have been offered new experiences without adequate planning, so that if they experienced failure they could be less likely to try again.

Bereavement
People with a learning disability who suffer bereavements may not receive the support they need. They may not understand what has happened, as the concept of death is abstract and intangible. They may not get an opportunity to talk through their feelings or come to terms with the bereavement. Sometimes bereavement can lead to other significant changes such as a move to emergency residential care. It means that people not only lose a carer but also their home and routines. Routines are very important and loss of that routine can be difficult to cope with. Section 4 provides more information on supporting people through bereavement.

Choice
All people with a learning disability have the right to make their own decisions. Some may need support to make decisions. Choice is very important to an individual's well-being. It gives them control over their lives, from making small day-to-day decisions such as what to eat, to life-changing choices such as moving home. Not being able to make choices or having choices ignored has a detrimental effect on mental health.

2.3 Physical factors

Physical factors relate to genetic makeup and how physical health interacts with mental health. They include:

Physical health problems
People with a learning disability are often susceptible to physical health problems. Being physically unwell can have a negative effect on general well-being and may lead to poor mental health. This is discussed in more detail in Section 4.

Physical disabilities (including sensory impairment)
People with a learning disability, especially those with severe and profound learning disabilities, are more likely to have physical disabilities. People with chronic physical disabilities are at increased risk of developing mental health problems, especially depression.

People with sensory impairments are at a greater risk of developing mental health problems, especially those with hearing impairments. A hearing impairment can lead to social isolation and misinterpretation of situations. Mental health problems are more likely when the sensory impairment occurs later in life, i.e. there is an increased sense of loss.

Communication problems
Communication and language problems can have an unfavourable effect on mental health. Some people with a learning disability may not be able to express their

feelings, and feel frustrated and angry. Sometimes they may use actions to communicate, but those changes in behaviour may, in turn, be misinterpreted as a phase and not acted upon with appropriate support. Moreover, challenging behaviour can occur in people as a result of difficulties in expression, emotional pain or distress.

Medication
The unwanted effects of medication, whether for physical or mental ill health, can lead people to develop mental health problems. For example anti-depressants can sometimes precipitate a period of hypomania. Medication that is given to treat high blood pressure can sometimes contribute to the development of depression. The unwanted effects of medication can sometimes be worse for the person than actually living with the condition they are being treated for and they may decide not to take the medication. People with a learning disability may be taking a number of medicines, and so are at particular risk of unwanted side-effects, particularly if the prescriber does not regularly review these.

Drugs and alcohol
The use of illegal substances, the abuse of alcohol and over-the-counter medicines can increase an individual's vulnerability to mental health problems.

Syndromes and developmental disorders
Some genetic syndromes are associated with having a learning disability. Conditions such as Down's syndrome and Fragile X are two of the most common syndromes associated with having a learning disability. Some of

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these syndromes are also associated with mental health problems, for example, those with Down's syndrome are at increased risk of Alzheimer's disease; those with Prader-Willi syndrome are more likely to develop eating disorders; and autism has been associated with an increased risk of anxiety and depression.

2.4 The interaction of social, emotional and physical factors

Social, psychological, emotional and physical factors interact. If a person has one of these factors it can often lead to them encountering another factor. For example, having a chronic physical disability (physical factor) may change the way we think about ourselves (psychological factor) and how others view us (social factor).

Protective factors
As well as factors that increase vulnerability to mental health problems there are a number of factors that can help protect someone from developing a mental health problem. These are discussed later in Section 4.

Section 3: Policy context

3.1 Introduction

In the past, the mental health needs of people with a learning disability have been overlooked at a local and government policy level. There has been a lack of awareness that individuals with a learning disability may have mental health problems. Also, there was a lack of research demonstrating the true prevalence of the issue.

More recently, a greater understanding of the mental health needs of people with a learning disability has been reflected in government policy. Government policy is conveyed through white papers (statements of what the government wants to happen) and legal frameworks (laws) such as the Mental Health Act.

3.2 Historical perspective

The majority of people with learning disability have been cared for by their families. During the Victorian era, families were encouraged to place their relatives with a learning disability into large institutions, particularly if they had complex needs, including challenging behaviours and mental health problems.

In the latter half of the twentieth century the move away from institutional care began. White papers such as 'Better Services for the Mentally Handicapped' (1971) stated the government's intention that people with a learning disability should have their needs met in the community. Other reports and frameworks have since

been published and now the vast majority of people with a learning disability live in the community.

Traditionally, many people with a learning disability have had their mental health needs met through specialist learning disability services with little access to mainstream services. However, policy guidance now emphasises that mainstream services should be accessible to people with a learning disability. This section outlines the relevant policy documents. The different services involved in providing mental health care, their interfaces and coordination of input are discussed in Section 5.

3.3 Government policies and legislation

The Mansell Report (1992)
One of the first steps to address the mental health needs of people with a learning disability was the Mansell Report (Department of Health, 1992). The report was based on the findings of a taskforce that was commissioned to provide guidance on how services should be developed for people with a learning disability with challenging behaviour or mental health needs. Key recommendations of the report included:

- Services should develop highly individualised care packages to meet the complex needs of these groups.
- Services should be small-scale and community-based.
- Specialist services should be provided locally.

The report was mainly aimed at those with challenging behaviour and did little to address the needs of people

with mental health problems who did not display such behaviour.

National Service Framework for Mental Health (1999)
There has been a variation in the level of health and social care that people receive in the United Kingdom, depending on their geographical location. In 1999 the government sought to rectify this by introducing National Service Frameworks (NSFs). These aim to reduce the variations by setting quality standards. They have been developed for a number of areas of health and social care including heart disease, cancer and services for older people and children.

In 1999 the *National Service Framework for Mental Health* (DoH, 1999) was published. It sets standards for mental health provision that aim to address the social exclusion and discrimination associated with mental health problems; to increase the effectiveness of care people receive in hospital and in the community; and to improve access to primary care services. There are also standards regarding support for carers and actions that are needed to reduce suicide rates in people with mental health problems. These standards were reviewed in 2004.

The NSF for Mental Health discusses the particular needs of many minority groups but does not highlight the needs of people with a learning disability. A statement was issued shortly after its publication stating that the NSF was applicable to all adults of working age, including people with a learning disability.

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This means that people with a learning disability have the same right to mental health care as other citizens.

The Care Programme Approach (CPA)
One of the fundamental aspects of the NSF for Mental Health is the use of the Care Programme Approach (CPA) for the coordination of mental health care. All patients of a mental health service in England should be on the CPA. However, its implementation for people with a learning disability who have mental health problems has not been universal. CPA provides a framework so that all services and professionals involved in the care of a person with mental health problems work in close collaboration, in a multi-disciplinary team.

Each person under CPA has a care plan developed to meet his or her needs, and a named care coordinator. Good practice dictates that CPA should be linked to the individual's Person Centred Plan and Health Action Plan. The CPA process and its outcome should be informed by the Person Centred Plan and it should be viewed as one process. The CPA care plan should be holistic and look at a wide range of issues aimed at not only addressing the person's mental health problem directly but also those areas which contribute to a person's well-being and that help them stay mentally well, e.g. day time activities, relationships, housing and physical health. The CPA care plan includes details of:

- the named care coordinator and those involved in the person's care
- a detailed risk assessment and management plan

- specific care plans regarding the individual's treatment and safety
- medications and side effects
- signs of and action required if the person becomes unwell again, e.g. emergency procedures, contingency plans or a crisis plan
- the people responsible for implementing the various parts of the care plan, with relevant timescales.

The care coordinator has overall responsibility for coordinating the person's care package. They are responsible for ensuring that the assessment is completed, that a care plan is devised and implemented, and that it is regularly reviewed with the individual and others involved (support staff, professionals, family members and advocates). It is vital that if problems arise or if members of the multi-disciplinary team or carers/support staff wish to change any aspect of the care plan that this is discussed with the care coordinator as soon as possible. See Section 5 for an example of CPA being implemented and services working in collaboration.

There are two levels of CPA: standard and enhanced. The multi-disciplinary team decides what level of CPA is required.

Standard CPA
This is for people who are more able to manage their mental health problems and pose little danger to themselves or others. They are more likely to have a support network and maintain contact with services but may require low-key support from a community psychiatric nurse (CPN) or mental health support worker.

Enhanced CPA
This is for those who have more severe or enduring mental health problems, have been detained under the Mental Health Act (see below) or require support from a number of different agencies. The care coordinator for an enhanced CPA is usually someone who has been clinically trained.

CPA enables a consistent approach to a person's mental health care. People may receive support from a range of services and agencies (see Section 5) and the care plan lays out their respective responsibilities in relation to the particular individual.

Valuing People: A new strategy for learning disability for the twenty-first century
The government's white paper 'Valuing People' (2001) outlines how services for people with a learning disability should be delivered in England. It was the first white paper on this issue for 30 years. It has four key principles of **rights, independence, choice and inclusion** for people with a learning disability. It promotes partnership working and it takes a wide-ranging approach incorporating health, social care, education, transport and leisure.

'Valuing People' recommends a person centred approach in service design and delivery. Person centred approaches are about engaging with the people that use services, listening to what they want and supporting them to live in local communities as they choose. Services should be flexible in their approach and should use resources to provide a service that the

person wants as well as needs. It is about adapting services around individuals and not placing people into rigid and pre-existing services.

'Valuing People' also offers some specific guidance on meeting the mental health needs of people with a learning disability, including:

Promotion of positive mental health
- Services should provide accessible information information that people with a learning disability can understand) on staying mentally well and the types of support they offer.
- The white paper also aims to improve access to education, housing and employment, which have a positive impact on mental health.

Access to generic services
- Wherever possible, people with a learning disability should use mainstream services to have their mental health needs met. This means that when people with a learning disability have mental health problems they should be able to access the same services as everyone else. This may be in the community or within an in-patient hospital setting. It recognises that people may need extra support to access such services and that service providers may also need support to offer this (for example training, advice).

Specialist services
- The white paper emphasises the role of specialist staff in supporting mainstream services. It also recognises that some people with a learning disability may benefit from specialist in-patient or community-based services.

Use of the Care Programme Approach;
- People with a learning disability should come under the umbrella of the Care Programme Approach if they have mental health problems and this person centred approach will incorporate a Health Action Plan.

'Valuing People' relates to England. Other parts of the United Kingdom have their own similar policies:

- Scotland: Same As You (Scottish Executive, 2000)
- Wales: Fulfilling The Promises (Welsh Office, 2001)
- Northern Ireland: Equal Lives (DHSS, 2005).

Green Light Toolkit (2004)
In June 2004, *Green Light for Mental Health: How good are your Mental Health Services for people with learning disabilities?* was published to help provide a framework for local services to implement the NSF for Mental Health, for people with learning disability.

It was developed by the Valuing People Support Team (who are charged with facilitating the implementation of 'Valuing People'), the National Institute for Mental Health England, (who implement the NSF for Mental Health), charities, people with a learning disability and carers. It outlines what people with a learning disability and mental health problems are entitled to expect from services, and highlights key challenges to services in meeting these. It contains a self-assessment tool for services to consider and to provide a framework for actions for improvement. The results of the assessment can be used as a baseline to measure progress over time. It uses a 'traffic light' system with scores of red, amber or green depending on the quality of the working practices of the services.

The Green Light Toolkit covers the following main areas:

- Local partnerships between mental health and learning disability services, primary care, people with a learning disability and their carers. This requires the development of joint protocols to ensure people receive the services they need.
- Local planning by local organisations to plan their services to meet mental health needs and plan how they are commissioned.
- The key mainstream mental health services that should be accessible to people with a learning disability.
- Care planning and the implementation of CPA and the development of a clear agreement between services regarding responsibility for CPA.
- Diversity of provision, including ensuring there are culturally specific services, that there are services and initiatives led by people with a learning disability and that people have access to a wide range of voluntary mental health services.
- Underpinning programmes that support an effective service, for example workforce planning and a workforce that is representative of the local population.
- Other priorities, such as the inclusion of people with a learning disability in local mental health promotion strategies and the Mental Health Act (1983).

The Green Light Toolkit advises that services should develop joint working protocols and liaison and training between mainstream and specialist staff to improve the care offered to people with a learning disability in mainstream mental health services.

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Mental Capacity Act (2005)

The Mental Capacity Act provides a legal framework for acting and making decisions on behalf of adults over 16 who lack the mental capacity to do so for themselves. The Act specifies the principles that must be applied by everyone who is working with or caring for adults who lack capacity. It also provides options for those who may choose to plan and make provision for a future time when they may lack capacity. The Act will come into force in April 2007.

At its heart is the fundamental principle that everyone must be assumed to have capacity to make their own decisions unless it is proved that they cannot. This is vital in preventing the rights of people with a learning disability from being ignored. It says that all people should be supported to make their own decisions as far as possible. A diagnosis will no longer be an acceptable reason to take away a person's right to make their own decisions.

People with a learning disability have the right to be supported in making their own decisions. There is an explicit requirement on professional carers to provide adequate and appropriate communication support to people with a learning disability to help them to participate as much as possible in the decision. This would mean that some people, particularly those who have very individual communication methods, are able to express their wishes and feelings before decisions are made. It is also important to consider how information can be made easier to understand (eg using pictures, symbols and talking tapes), if there are times and places

where it would be easier for the person to make the decision, and whether anyone else can help the person to make their decision. For example, if the decision concerns consent to medical treatment, the doctor will need to explain fully what is involved in the proposed course of treatment, and the consequences of consenting to or refusing treatment.

An assessment must be made of the person's capacity to make a particular decision at the time that the decision has to be made. A person may have capacity to make some decisions but not others. If someone lacks capacity to make one decision this does not necessarily mean they will then lack capacity for all decisions. Moreover, a person may learn new skills and be subject to new experiences, which increases their capacity to make certain decisions; for example, a person with a learning disability may move to live in supported accommodation and gain new skills as a result. Therefore, assessments of capacity to make certain decisions need to be reviewed periodically.

A person is unable to make a decision if he/she is unable to:
a) understand the information relevant to the decision
b) retain that information
c) use or weigh that information as part of the process of making the decision
d) communicate his/her decision (whether by talking, using sign language or any other means).

Anything done for a person who lacks capacity must be in their best interests. There is a best interests checklist

for people acting on behalf of others, which is contained in the Code of Practice accompanying the Act. This includes consideration of the person's wishes, feelings, beliefs and values and taking account of the views of their family and friends. The decision made should be the least restrictive alternative. It is important in considering a person's best interests to ensure that the person is involved in the decision-making process to the fullest extent. The fact that someone lacks capacity does not mean that the person cannot participate in the decision-making process. A friend, relative or independent advocate may be able to help the person express wishes or aspirations or to indicate a choice between options.

The Act's other key provisions are:

■ Protection to carers and professionals, subject to rules and limitations, to take actions on behalf of a person who cannot consent, without incurring liability.
■ Lasting powers of attorney (LPA), for people to appoint an attorney of their choosing to act on their behalf should they lose capacity in the future.
■ Deputies can be formally appointed to make decisions about matters in relation to which a person lacks capacity.
■ Creation of an Independent Mental Capacity Advocate service to support and represent people lacking capacity who have no one else to speak for them when decisions need to be taken about serious medical treatment and change in accommodation.
■ New safeguards controlling many types of research involving people who lack capacity.

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- A person, whilst they have capacity, if they so wish, can make an advance decision to refuse treatment, sometimes known as 'living wills'.
- The introduction of a criminal offence of ill-treatment or neglect of a person who lacks capacity, with a maximum sentence of five years.

The Act creates also creates two new public bodies:

- Court of Protection: The new court will have jurisdiction in relation to the Mental Capacity Act. It will have special procedures and judges.
- Office of the Public Guardian (OPG): This will take over from the current Public Guardianship Office. The OPG will be the registering authority for lasting powers of attorney and deputies.

Whilst the Act sets out the legal framework, the Code of Practice provides guidance and information for those acting under its terms and applying its provisions on a daily basis. Front-line staff who are working with people with a learning disability have a legal duty to have regard to the Code, and we would encourage everyone to follow its guidance.

When a person lacks mental capacity and a decision about serious medical treatment or where they live needs to be taken, an Independent Mental Capacity Advocate (IMCA) is appointed to support and represent them. The IMCA voices the person's wishes, feelings, beliefs and values and they make the decision-maker aware of all relevant information. An IMCA will be provided when someone with no friends or family to support them is faced with a decision about a serious medical treatment or change of accommodation.

Some people with a learning disability may at times be quite capable of making their own decisions and running their own lives, but may have an additional mental health problem. Temporary factors such as distress caused by bereavement may affect someone's ability to make their decisions. It may be possible to put off the decision until such time as the person has recovered and regained capacity to make their own decision.

The Mental Health Act (1983)

For the majority of people with a learning disability, the Mental Capacity Act (see above) will be the most appropriate guiding legislation. If a person also has a mental disorder and compulsory intervention is necessary, consideration should be given to the Mental Health Act.

The Mental Health (1983) Act sets out the circumstances in which an individual can be detained in hospital for assessment and/or treatment for their mental disorder without their consent. The Government has announced that they will introduce a Bill to amend the Mental Health Act (1983). The new 'amending' Bill is to be introduced in 2006.

The Mental Health Act (1983) exists primarily to provide a framework in which care and treatment can be given without consent to people who suffer from a serious mental disorder, which puts them, or other people at risk. In particular, it defines the circumstances in which mentally disordered people can be detained in hospital for assessment or treatment. It allows people detained in hospital to be treated for their mental disorder without their consent, subject to various safeguards. It defines the circumstances in which mentally disordered people can be made subject to guardianship or aftercare under supervision, and sets out the powers of guardians and supervisors.

The Mental Health Act (1983) is concerned only with the provision of treatment for mental disorder. People who lack capacity who are also subject to the provisions of the Mental Health Act (1983), will still be covered by the Mental Capacity Act in relation to other types of decisions or actions affecting them. Therefore, where a decision unrelated to treatment for mental disorder needs to be made (including decisions about physical healthcare, welfare or financial matters), an assessment must be made of the individual's capacity to make that particular decision at the time it needs to be made. Following a finding of lack of capacity, the principles and provisions of the Mental Capacity Act would apply to all such decisions or actions, regardless of whether the person was subject to the provisions of the Mental Health Act (1983).

The new Bill to amend the existing 1983 Mental Health Act will include 'Bournewood' safeguards through an amendment to the Mental Capacity Act. These safeguards are for people who lack capacity and are deprived of their liberty but do not receive mental health legislation safeguards.

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3.4 Mental health and social exclusion

People with mental health problems often suffer social exclusion, including unemployment, social isolation, homelessness, limited opportunities and barriers in accessing services. This was the subject of a government inquiry (Social Exclusion Unit, 2004). Its recommendations included:

- Reducing stigma and discrimination by challenging negative attitudes and promoting awareness of people's rights.
- Health and social care services supporting people to reintegrate into the community.
- Giving people with mental health problems a real chance of sustained paid work.
- Supporting people and giving them choices to lead fulfilling lives in their communities.
- Enabling access to appropriate housing, financial advice and transport.

3.5 Policy implications for commissioning

Often the commissioning of specialist services for people with a learning disability has been the role of learning disability commissioners, with different commissioners purchasing mainstream mental health services. As individuals with a learning disability and mental health problems begin to access mainstream services, a greater degree of dialogue and joint planning will be necessary between commissioning groups.

This may involve the pooling of budgets to ensure people receive the mental health care they need.

There are few services (both health services and in the voluntary sector) that are set up specifically for people with a learning disability who have mental health problems. This has resulted in significant numbers of people being placed out of area, sometimes miles away from their local communities and support networks. This will continue unless commissioners invest in locally-based services (mainstream and specialist) that can meet the needs of individuals with the most complex needs (e.g. severe challenging behaviour and forensic problems). For those individuals who do require a highly specialised service that cannot be delivered locally, systems need to be put in place that ensure regular monitoring of quality of care and contact with carers and friends.

Part B of this guide covers mental health promotion (Section 4), the range and type of services (Section 5), the assessment process which provides the gateway for individuals to access support and treatment (Section 6), and the different interventions that are available (Section 7).

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Supporting Complex Needs: A practical guide for support staff working with people with a learning disability who have mental health problems

Part B:
Supporting people and getting help from services

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Section 4: Working with people with mental health needs

4.1 Promoting positive mental health

Can we prevent mental health problems from developing in the first place?

There are lots of ways in which we can reduce the likelihood of someone developing a mental health problem or preventing those who have recovered from relapsing. This is called 'mental health promotion'. Mental health promotion is any activity that improves mental well-being. It is one of the government's health priorities and a standard is dedicated to mental health promotion within the National Service Framework for Mental Health (DOH, 1999).

As we have seen in Section 2, there are factors that can make an individual vulnerable to developing mental health problems. There are also factors that have been found to protect individuals from developing mental health problems. These 'protective factors' are most effective at reducing the development of anxiety, depression and behaviour disorders. Little research has been done regarding protective support for people with a learning disability, though we can learn from the research undertaken in those without a learning disability.

Can support staff do anything to promote mental health?

Support staff play a vital role in promoting positive mental health in those they support, and this can be done in a variety of ways. Most protective factors are based on common sense and are activities that support staff should be undertaking as part of their day-to-day work. However, when working with people who are particularly vulnerable or recovering from a mental health problem, support staff may need to make formalised plans to promote positive mental health.

> 'Support staff should help people to stay mentally well. They should support us to help ourselves.'
> *Person who uses services*

Working in a person centred way

Working in a person centred way means supporting people in a way that is tailored to what they want and need. It is about enabling them to achieve their goals, dreams and aspirations and supporting them to lead the life they want.

Person centred planning is different from other types of care planning as it is not based on what services think would be best for the person or what resources are available. Instead, services are flexible and designed around what an individual considers to be important from their own perspective. Services adapt and change to reflect the individual's needs. Supporting people with a learning disability in a person centred way is an essential part of promoting positive mental health.

> 'Everyone is different. We should be treated as individuals. We should be treated as adults.'
> *Person who uses services*

Choice and advocacy

People with a learning disability can often feel disempowered. It is important that services fully involve the person in all aspects of their care. People who use services should be supported to make choices, whether these are small choices such as what to have for breakfast or life-changing choices such as where to live.

> 'We have a right to speak up for ourselves. We can make our own choices.'
> *Person who uses services*

Sometimes people with a learning disability may need support to advocate their choices and decisions. This is where advocacy services can help. Many areas across the UK now have advocacy services for people with a learning disability. They can provide a range of services for the individual, including professional paid advocates when major decisions need to be made and peer groups where people can develop their self-advocacy skills. Some services provide citizen advocates. This is where the person with a learning disability is partnered with a local citizen, who is a volunteer and is not connected to local services. The citizen advocate develops a long term relationship with the individual, getting to know their likes, dislikes and wishes and ensures that the person's interests and views are at the centre of all decisions.

When a person has choice and control over their life, it shows them that other people respect, trust, listen to them and treat them as equals. All of these values promote a good sense of self-esteem.

Communication

When supporting people with a learning disability it is essential that staff help them understand the external

world, and that staff also understand them. This means communicating at the right level, using different methods appropriate to different people. Speech and language therapists can work with support staff in developing communication care plans. (Section 9 lists a number of websites that can support staff in making information accessible.)

Family
Being part of and having regular contact with a strong supportive family is an important factor for positive mental health. It is vital that staff support individuals in maintaining relationships with their families and involve them as much as possible in the person's care (with the person's consent). Support staff should view families as partners in the care process and engage them accordingly.

Good physical health
People with a learning disability are at risk of experiencing poorer physical health than other people and are more susceptible to certain conditions such as epilepsy, thyroid disorders, sensory impairments and stomach problems. They may have difficulty in recognising or reporting poor health and may have limited awareness of the benefits of good diet and exercise. Many may also be unaware that good physical health helps promote positive mental health.

Staff can support the development and implementation of Health Action Plans for individuals, in collaboration with the local community teams for people with a learning disability. They can ensure that people receive regular health checks with a GP or practice nurse and

also regular dental, visual and hearing checks. They can also support them to improve their health through promoting a good diet and regular exercise. Staff can also support individuals to access health education programmes at local colleges or health centres and exercise programmes/classes at leisure centres.

Building social networks
Supporting people to develop their social networks is an important role for support staff. Individuals should be supported to develop relationships and friendships. This can include supporting them to participate in their local communities, use public facilities and access befriender schemes. To develop social networks, it may be necessary to develop a person's social skills first. Support staff can help the person gain and develop these skills. Some colleges run courses for people with a learning disability in this area. Speech and language therapists and occupational therapists can also help build social skills. The move towards social inclusion must become a realistic goal to be achieved.

> **'Having friends is good for your mental health. I would like a girlfriend as well.'**
> *Person who uses services*

Predictability
Life is often worrying for people with a learning disability. Sudden changes in routine can cause increased levels of anxiety. Support staff need to make life predictable by using a variety of methods to introduce routine and keep the person informed, e.g. by using visual timetables, diaries or prompts.

Employment and meaningful day time activities
Having a job is one of the most valued positions in society. It can provide an income, contribute to an individual's feeling of self-worth and provide opportunities to develop social networks. Some organisations offer training to develop the skills to have a job. This might include developing interview skills or supporting the person to find a job and then providing on-the-job support until the person gains confidence. Support staff can find out about these organisations from their local social services or Community Team for People with a Learning Disability (CTPLD). For more information about CTPLDs, see Section 5.

There are opportunities for people who do not have or do not want a job. Emphasis should be placed on what the person wants to do and achieve and the individual's wishes should be supported through their Person Centred Plan. Meaningful activities may include:

- Accessing a wide range of educational opportunities at local colleges or adult education centres.
- Community activities, for example at the local leisure centre, various community groups, taking up hobbies and interests and volunteering.
- Local authorities or voluntary organisations often provide day service provision. Most local authorities are modernising their day service provision and moving towards supporting people to develop a wide range of skills to become active members of their local communities.

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All people, including those with a learning disability, change and develop over time, and this may alter their interests and choices. Activities should therefore be flexible and regularly reviewed with the individual through their Person Centred Plan.

> 'I get bored staying at home. I like to keep busy. My keyworker helped me get into college. I'm learning how to use the internet.'
> *Person who uses services*

Responsibility and achievement
Having responsibility gives opportunities for achievement and indicates that a person is respected and trusted by others. High self-esteem promotes mental well-being. Achievement improves self-esteem and self-worth, and this is particularly true if achievement is recognised by others. Support staff should provide opportunities for responsibility, for example in aspects of the running of the person's own home. Individuals should be given encouragement to succeed and their achievements should be recognised.

There are many educational opportunities for people with a learning disability at local colleges and adult education centres. Here people can develop their skills, broaden their social networks and achieve positive outcomes. Furthering education may also lead to increased opportunities for employment.

Diversity
The UK population is diverse in many ways, including ethnicity, culture, religious beliefs and sexual orientation.

Recognising diversity and the needs associated with it are very important for mental health. Support staff should ensure that diversity issues are respected and are included in all aspects of care planning and delivery. This can include ensuring specific cultural dietary needs are met, religious practices and festivals are followed, communicating in different ways and offering opportunities for the individual to socialise with people with similar needs and beliefs.

Feeling secure and safe from harm
Feeling secure and safe from harm in both the home and local community is important for mental health. People with a learning disability may live in supported housing with people whose behaviour is challenging (see Section 1 about challenging behaviour). Aggression should not be accepted or tolerated. If it occurs this should be immediately reported to the manager and risk management guidelines put in place. Specialist services may need to be involved to assist the service to find the appropriate solution. Under the Protection of Vulnerable Adults guidance, support and care staff have a duty of care to protect the people they are supporting.

It is not uncommon for people with a learning disability to be bullied or to be victims of crime. Serious incidents should be reported to the police. Support staff can contact their local community police officer who provides advice and support on staying safe in the community.

Experiencing aggression or crime at home or in the community can affect mental health. Support staff may need to discuss with the victim if they would like some

form of counselling to help them manage what has happened.

4.2 Supporting people who experience emotional distress

There are times in our lives when we may experience high levels of emotional distress. This is natural and is often a response to something that has happened in our lives, for example experiencing bereavement or loss. Although this does not normally require specialist input there are a wide range of interventions that support staff can implement to improve the person's state of mental health. People will require specialist input when the symptoms are severe and impact on the individual's overall functioning, affecting many aspects of the person's day-to-day life.

Supporting people through change
Dealing with change is a factor that may cause emotional distress. Such changes include leaving school or moving house, and these are often referred to as transitions. People with a learning disability may experience numerous transitions and they should be empowered to make their own decisions and choices about such change.

A transition for people with a learning disability often provokes anxiety and can produce stress reactions, even if the transition is the person's own choice. This can significantly increase vulnerability to mental health problems, particularly if the person has little or no

control of the events and situation. If transitions are well-managed they are less likely to have negative consequences and can have benefits by providing new opportunities for the person.

Staff can positively support people through change, for instance:

- Staff can be proactive and forward-looking. They can identify future transitions/changes and ensure they and the individual have adequate time to prepare.
- The planning and implementation of change should be person centred, involving the individual as much as they want.
- Discuss the change with the person and offer reassurance as frequently as required. Also give the person accessible information about the transition that they can consider on their own.
- Provide as much information as possible to the person about the transition in a format they understand (e.g. verbal communication, symbols, photos).
- Offer as much choice as possible.
- If it is a planned transition, introduce the new situation gradually.
- Maintain predictable and familiar aspects as much as possible.
- Once the transition is complete, maintain links with the environment that the person has left.

Positive practice example

Paul is 52 and has a learning disability. He has lived with his mother all of his life. His father died some years ago. He has no brothers or sisters or other family. Paul works part-time in a horticulture centre and attends the local college.

Over recent months Paul's mother has become more and more fragile and it is likely that she will need to go into a nursing home within the next few months. Paul's mother has asked his care manager to help them think about his future.

The care manager has been meeting with Paul and his mother regularly to discuss with him what's happening to his mother and what he wants to happen in the future. He is sad that he will leave but with support he understands that it needs to happen. Paul has decided that he would like to move into a local supported house with other people who have a learning disability.

Paul's care manager found two supported houses that he could possibly move into. Paul and his mother visited both several times. He chose to move into a house where people were about his age and where he knew one of the people from college.

As Paul's mother was becoming more fragile, a planning meeting was held the following week. Paul and his mother attended the meeting with the house manager and support staff. A moving in date was set for six weeks' time and a plan of action was agreed by all,

which included:
- Paul will visit the house regularly over the next six weeks, starting with short visits gradually working towards over night stays.
- The house staff will spend time with Paul at his house. They will talk with him and his mother about his routine, likes and dislikes and how he would like to be supported.
- Paul will choose the décor and furniture for his bedroom.
- The staff team will support Paul to become orientated to the local area.
- Paul, his mother and staff will make sure he takes personal effects to maintain identity.
- Staff will ensure Paul is supported to maintain contact with his friends.

Paul has now moved into his new home. He decides to have a few days off work and college so he can get used to his new home. The staff team support Paul to visit his mother several times each week and to phone her whenever he wants.

The first month is quite stressful for Paul; as well as moving into his new home, his mother's health is deteriorating and she will soon be moving into a nursing home. There have been times when Paul has become anxious. He tends to become more anxious when too many demands are placed on him or he feels surrounded by other people. He has expressed his anxiety by being short-tempered, shouting at others and hitting several people. Paul and his keyworker have

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met to discuss how he is feeling and have developed a care plan on how the staff can best support him. The care plan includes:

■ Regular scheduled opportunities to discuss how he is feeling, as well as talking to staff as often as he needs to.
■ Recognising possible triggers for Paul's anxiety.
■ Teaching Paul to recognise when he is becoming anxious.
■ Teaching Paul strategies to deal with his anxiety, such as relaxation.
■ Reducing the likelihood of the triggers occurring.
■ How to intervene before Paul loses his temper.
■ Strategies on how to react to Paul if he loses his temper.

After a couple of months Paul has settled into his new home. He is seeing his mother regularly at the nursing home. The staff team has consistently implemented the care plan for Paul's anxiety and his anxiety has greatly reduced.

n.b. We will return to this positive practice example later on in this section.

Supporting people through loss and bereavement

Experiencing loss and bereavement is a life event that people will go through at some point in their lives. It will often cause emotional distress, with individuals experiencing a number of stress reactions including sadness, anger, frustration and becoming socially withdrawn. Many people develop their own coping strategies to support themselves at these times. People with a learning disability may find it more difficult to understand and cope with such events. They may need additional support to help them come to terms with their loss and express their grief.

There has been a tendency to protect people with a learning disability from the concept of death and loss. Although done with good intentions, this denies people with a learning disability opportunities to be involved in making important decisions about those they care for and takes away their right to grieve and go through the stages of the grieving process. Here are some practical ideas on supporting people through these times.

Supporting people before and after a death

Supporting people before a death
■ Create opportunities to talk. Check the person's understanding about what is happening and what will happen in the future.
■ Use clear words and check that the person understands what you said.
■ Gain an understanding of the person's bereavement history (i.e. loss of family members, friends). How were they supported? How did they react?
■ Familiarise people with the concept of death and the customs associated with it. Use opportune moments to discuss the concept of death, such as when soap opera characters or famous people have died.
■ The death of a family member can often lead to other losses, such as moving home. These losses should be anticipated and prepared for, with the individual being fully involved in any decision-making. (Adapted from Lynggaard, 2002).

Supporting people after a death
■ Be open and honest about what has happened.
■ Do not shield the person from what has happened or treat them like a child.
■ Do not use child-like or alternative explanations for what has happened (i.e. making excuses for where the person is).
■ Do not avoid the subject of the person who has died. Use naturalistic opportunities to talk about the person and explore memories. If natural opportunities do not occur, set specific time aside to talk with the person, but do not pressure them.
■ The person could be supported to develop a memory book. If they have a life book or story, ensure that the loss is explored and included in it.
■ Support the person to be involved in culturally appropriate customs (e.g. ordering flowers).
■ Encourage and support the person to attend funerals and memorials. The person could be supported to visit the crematorium or cemetery beforehand, to help reduce anxiety and stress.
■ Allow time for the person to grieve.
■ Be aware that bereavement reactions may be delayed, or may be triggered by other losses (e.g. keyworker leaving).
■ Remember that people grieve in different ways and at their own pace.
■ Some people may find it difficult to communicate their grief. If the person's behaviour becomes

challenging at this time it is likely to be an expression of grief. This should be reacted to with empathy and understanding.

- Ongoing support is important, especially at anniversaries and special festivals such as birthdays.
- If you or the team is unsure about the support you are giving the person, seek advice.

(Adapted from Lynggaard, 2002).

Positive practice example

Paul has now been living in the supported house for a year. He is enjoying his new home; he has developed a good relationship with his housemates and staff. He has been visiting and phoning his mother regularly. He now works at the horticulture project full-time and is thinking of undertaking an NVQ in horticulture.

Paul's mother has recently contacted the house manager to tell her that she is terminally ill. It is likely that she will pass away within the next three months. She is very worried at how Paul will deal with this and would like to meet with the manager to discuss her fears and how they will tell Paul, as he did not react well when his father died. They agree that his mother should tell him with the support of his keyworker.

Paul's keyworker thinks they might need some information to help Paul understand about his mother's illness and that she is going to die. He contacts the local Community Team for Adults with a Learning Disability who loan them some accessible information on terminal illness and coping with someone close dying.

They tell Paul what is happening at his next visit. He says he understands what has been said but doesn't really say much about it. Over the next few days Paul is quiet and refuses to talk to his mother when she telephones. He is also refusing to go to work and is spending most of the day in his bedroom. The staff recognise that this is a difficult time for Paul. They do not pressure him but let him know that they are there to support him and that he can talk to them whenever he wants. His keyworker spends specific time with Paul every few days going over what his mother told him and uses the accessible information to help him understand she is ill and what death actually means. He also gives Paul a copy of the information. This appears to be helping. Paul has lots of questions and relates a lot of what is happening to when his father was ill.

Over the next few months his mother's health worsens. Paul sees her frequently during this time. During the visits with his mother, Paul supports her in making arrangements for her funeral, such as meeting the priest who will conduct the service, choosing the coffin and deciding on the hymns and flowers. Staff give him ongoing support and reassurance, especially before and after his visits. They have revisited his care plan for anxiety and included recording his mood, as they are worried he might become depressed. They also record physical factors such as sleep and eating patterns as they can indicate emotional distress. His keyworker still spends specific time with him talking about his mother, her death and how he is feeling now and is likely to feel.

Paul's mother sadly passes away the following month; he was with her when she died. Paul is supported to make the final arrangements for the funeral and invite people to attend. Paul is quiet leading up to the funeral, but meets daily with his keyworker and seeks the support of staff as required. The funeral goes smoothly and with the agreement of his housemates, a wake is held at Paul's home.

As the staff expected, there have been a number of occasions when Paul has been upset, but there have been no instances of him losing his temper or hitting anyone. The team have been very proactive in supporting Paul and in anticipating his needs. His keyworker has supported him in developing a memory book about his mother.

A few months on and Paul is doing well. He often speaks about his mother and regularly uses his memory book. He visits the cemetery every couple of weeks.

He is now at college a day a week doing his NVQ and has made several new friends around where he lives.

Resources

There are a number of resources that can support staff in discussing issues of death, loss and change with people who have a learning disability. These are listed in Section 9.

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Section 5: Getting help and understanding the mental health system

5.1 Recognising mental health problems

How can you tell if someone has a mental health problem?

It can often be difficult to recognise the early stages of mental health problems. Support staff may recognise changes in an individual that alert them to the possibility of a mental health problem. Section 1 outlines the changes in behaviour and functioning that support staff need to watch out for. We are crucially looking for changes from what is normal for the person.

Could these changes indicate something other than a mental health problem?

Yes. Changes in behaviour, functioning and thinking do not necessarily mean that the person has a mental health problem. These changes could be due to other considerations including physical illness.

Do mental health problems look the same in people with different degrees of learning disability?

Their presentation depends on the person's level of functioning and how they communicate their thoughts and feelings to others. For people with a milder learning disability the presentation of mental health problems is similar to people who do not have a learning disability, though they may need extra support explaining how they are feeling. People with a more severe learning disability and those who have significant difficulty in communicating their thoughts and feelings are more likely to show some different changes. These may include challenging behaviour such as aggression and self-injury. As discussed in Section 1, it is when there is a change in an individual's behaviour, mood or thinking that particularly alerts us to the possibility of a mental health problem.

5.2 Getting help

What should we do if we think a person has developed a mental health problem?

The staff team should discuss the issue as soon as possible. The team should make a list of all the changes they have observed in the person's behaviour and record the reasons why they are concerned. It is important to talk to all the staff team, as the individual will have different relationships with all of them and some staff may have supported the individual more than others.

The staff should also discuss their concerns with the individual. Often the person's keyworker would be the best person to do this. They can encourage and support the person to seek help. If the person agrees, then thought should be given as to who is the most appropriate person to approach first. Often this will be the person's GP. Sometimes it may be someone else that the individual knows or prefers, e.g. a nurse who visits the day centre, a drop-in service. In cases where someone with a learning disability is already known to local learning disability or mental health services, staff should contact these services first.

If the person is unwilling to seek help, this must be respected. However, if they are at risk because of this decision, staff should discuss with their managers how to proceed.

It is important that someone that knows them well, preferably their keyworker, offers the person support when they visit the GP, nurse, etc. They should be supported to say what the problem is and how they have been feeling. The staff member (with the person's consent) should also explain the concerns of the staff team, emphasising the following:
■ what changes have occurred
■ when they started
■ why they concern the staff team
■ how the changes are affecting the person's day to day life.

If the practitioner believes that there is a mild mental health problem they may provide treatment themselves. If it is more severe, or they think the person could benefit from more specialised support they may refer the person to local mental health services.

What if it is an emergency situation?

If it is an emergency situation, for example if the person is talking about suicide, and the staff team cannot manage the person at home, it may be appropriate to call the person's GP who may do a home visit or arrange for their community psychiatric nurse to visit. It may be appropriate to arrange respite care or some time in hospital.

Alternatively, it may be appropriate to accompany the person to the accident and emergency department at

the local hospital, bearing in mind that it is always advisable to involve the person in all decisions. The information provided by support staff, as above, will inform the assessment process in the hospital.

5.3 Services for people with a learning disability who have mental health problems

Why do some people use mainstream mental health services and some people receive mental health input within learning disability services?

It is government policy that people with a learning disability use mainstream mental health services whenever possible (see Section 3). Specialist Mental Health in Learning Disability services provide advice and support to mainstream services and deliver mental health care to those who have difficulty accessing mainstream services. There are no national criteria regarding which groups of people should use mainstream services and which should use specialist services. This is a clinical decision, which may be guided by locally-developed protocols and is based on the needs of the individual. When deciding which service would best suit an individual, the following should be considered:

- The choice of where the person would prefer to receive mental health care.
- The vulnerability of the person and how best to manage any risks.
- The skills of the staff team in assessing and treating the person with a learning disability. It is important to

ensure that expertise in learning disability is available alongside expertise in mental health so that the preventative, early intervention services work effectively with and for people with a learning disability.

People with a learning disability should have equal access to mainstream services. People with complex needs, whose vulnerability cannot be managed in mainstream services and require specialist support in communicating their needs will benefit from accessing a specialist service.

5.4 Mainstream and specialist services

What support is available to people with a learning disability who have mental health problems?

Over the last two decades there has been a move from institutional care to community-based services for people with a learning disability (see Section 3). People with a learning disability can now access the full range of mainstream services available for people with mental health issues, described below.

Primary care services

If a person has concerns about their health they will usually access primary care services, which include health centres and general practitioner (GP) surgeries. These services assess and treat 'common mental health problems' including mild depression and anxiety disorders and also have a role in monitoring more complex or ongoing mental health problems. Primary care services are also the gateway to specialist and

Support available to people with a learning disability and mental health needs

secondary services. If the mental health problem is severe and/or enduring, the primary care service will refer the individual onto specialist mental health services or specialist services for people with learning disability.

Specialist learning disability services

The NHS and Social Services provide specialist learning disability services across the UK in the form of Community Teams for People with a Learning Disability and specialist in-patient units.

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Community Teams for People with a Learning Disability (CTPLD)

CTPLD provide specialist health and social care assessment and intervention to people with a learning disability. They work closely with a variety of people and services such as families, residential and day service staff and mainstream services to improve the quality of life of people using services. The teams are situated in the local Primary Care Trust, social services and occasionally the Mental Health Trust. They usually consist of:

- care managers/social workers
- clinical psychologists
- community learning disability nurses
- occupational therapists
- physiotherapists
- psychiatrists
- speech and language therapists
- workers trained in dealing with challenging behaviours.

Many CTPLDs provide community-based assessment and treatment of mental health problems, though this is not their primary function or speciality.

In-patient services

Some learning disability services have a local in-patient ward. These wards generally have fewer beds than mainstream wards. They may admit people with severe mental health problems, but many also admit people with challenging behaviour or those whose community placement has broken down. They are staffed by learning disability nurses and support staff, with regular input from psychiatrists and therapists as required.

Specialist mental health services

Specialist mental health services are provided in the UK by NHS Trusts. They provide community and in-patient services and are usually divided into services for people with different needs and/or different age groups.

Community services

These are normally based at an accessible location and include a range of professionals, including: clinical psychologists, community psychiatric nurses, occupational therapists, psychiatrists and social workers.

- Child and Adolescent Mental Health Teams (CAMHTs) provide assessment and treatment for children up to the age of 18.
- Community Mental Health Teams (CMHTs) provide assessment and treatment for adults of working age.
- Community Mental Health Teams for Older People provide assessment and treatment for people over the age of 65.
- Assertive Outreach Teams (AOTs): community-based teams that can provide a 24-hour response to people who are at high risk of losing contact with services.
- Crisis Intervention/Home Treatment Teams: community-based teams that can provide intensive support and treatment to people in their own homes who would otherwise need to go into hospital.
- Early Intervention for Psychosis Teams: community-based teams who specialise in working with young people who are experiencing their first episode of psychosis.

- Community Drug and Alcohol Teams: work with people who have issues with substance misuse, and also have severe mental health problems.
- Community Forensic Teams: work with people who have committed, or at risk of committing offences, who also have severe mental health problems.
- Specialist Mental Health in Learning Disability (MHiLD) services: some areas have teams that are specifically dedicated to the mental health needs of people with a learning disability. The teams are multi-disciplinary and are community-based. They are often part of the local mental health services. These services may also have specialist in-patient services specifically for assessment and treatment of people with a learning disability who have severe mental health problems.

In-patient services

Hospital in-patient wards are for people with severe mental health problems who cannot receive assessment and treatment in the community. They have on average 15–20 beds and are separated by age group, i.e. wards for children and adolescents, adults and older people. Some areas may also have secure units for people with mental health problems who have committed offences. In-patient wards are staffed by mental health nurses and health care assistants, with regular input from psychiatrists, occupational therapists and other professionals.

5.5 How do mainstream services and specialist services interact?

The vast majority of people with learning disability who have mental health problems have their needs met by community services, whilst remaining in their home. Some people with severe mental health problems who are in crisis may be admitted into hospital. This is generally for a short period for assessment and treatment, and less commonly for longer periods for stabilisation and rehabilitation. As discussed in Section 3, when local services are unable to meet complex mental health needs, people sometimes receive treatment outside of their local area. This is not seen as good practice and should only happen in exceptional circumstances. Every effort should be made to meet the person's needs locally.

The mental health care of people with a learning disability is not the sole responsibility of any one service. As we have seen there are a range of services that can work with people with a learning disability who have mental health problems. It is highly likely that an individual will receive and benefit from input from a number of these services so it is essential that services work in partnership. Effective coordination is vital when a variety of agencies and professionals are supporting people. This places the implementation of CPA at the centre of mental health care.

As we have seen in Section 3, the Green Light Toolkit has been developed to promote collaboration, especially between mainstream mental health and specialist learning disability services. It advises that services should jointly develop protocols that enable people with a learning disability to access mainstream services wherever possible. Protocols should highlight how services will interface with and support each other, define roles and responsibilities and lay out a clear pathway of care for the person with a learning disability.

The period of time that has elapsed since the advent of mainstream service access and the promotion of the Green Light Toolkit has been short. In reality the development of protocols between services is in its infancy and many areas have not begun to address this issue. Additionally, where there has been progress, there may still be boundary disputes between services as to who should provide support and hold responsibility. Whether or not disputes occur, it is important that the care of the person is central and that a clear plan is developed to meet their mental health needs through CPA.

5.6 What professionals work in these services and what do they do?

Both mental health and learning disability services are multi-disciplinary and may be multi-agency. They have a range of staff with specialist skills and knowledge.

Clinical psychologists
Clinical psychologists are trained to assess and treat the emotional distress that is associated with mental health problems. They use a variety of 'talking therapies' such as cognitive behaviour therapy and counselling. These are described later in Section 7. Clinical psychologists who work in learning disability services may also assess if a person has a learning disability or if they have the capacity to give consent. They support people by working directly with the person and by developing behaviour management guidelines with the support staff.

Challenging behaviour workers
Some learning disability services employ challenging behaviour workers. They come from a range of professional backgrounds. They assess the person and their environment to find out why they behave in a particular way and develop intervention packages to replace the challenging behaviour with more appropriate ways of behaving and improve the individual's quality of life.

Community learning disability nurses
These are registered nurses working in the field of learning disability and they work with individuals to improve, maintain and promote good health.

Community psychiatric nurses (CPN)
A CPN is a registered mental health nurse who works in the community supporting people in their own homes. They work closely with others to assess, monitor and implement treatment for mental health problems. Some CPNs are specialists in working with people who have a learning disability.

Occupational Therapists (OT)
OTs support people to develop and maintain the skills needed for everyday living, such as cooking, hygiene and

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budgeting. They also assess people for potential aids and adaptations that may support them to be more independent. OTs assess whether accommodation is suitable to meet the needs of the individual and support people with a learning disability to integrate into their local communities.

Physiotherapists
A physiotherapist is a professional who is trained in how the human body works, especially in relation to mobility. They can treat a wide range of movement disorders and support and advise people with mobility problems.

Psychiatrists
A psychiatrist is a medical doctor who specialises in mental health. They assess, diagnose, treat and manage mental health problems. Some psychiatrists specialise in working with people with a learning disability.

Speech and language therapists
Speech and language therapists are specialists in supporting people to communicate and interact with the world around them. They are able to assess and treat a wide range of communication disorders and support services in making information accessible. They also provide assessment and advice on people with eating, drinking and swallowing difficulties.

Social workers
The role of a social worker is to assess whether an individual's social circumstances have contributed to them developing a mental health problem. They develop care plans to improve the person's social situation, such

as ensuring they have appropriate accommodation, access to other services and are receiving the right benefits. Some social workers called Approved Social Workers (ASW) have been specially trained to assess people under the Mental Health Act to see if they require admission to hospital.

Care managers
Some learning disability services employ care managers, who have a very similar role to social workers, but a qualification in social work is not always required. Other professionals such as nurses and occupational therapists can become care managers.

Other key services and stakeholders
Other services that play a key role in meeting the mental health needs of people with a learning disability include advocacy services, organisations supporting individuals into employment, and departments of the local authority, such as housing and voluntary services. These agencies are especially important in the promotion and maintenance of positive mental health. Partners, family and friends of the person with a learning disability are also vital in the planning and delivery of effective mental health care.

Positive practice example
Shazia is 43 years old and has a learning disability. She lives in a supported house with two other people who have a learning disability. Shazia is described as being a sociable person who gets on well with her housemates and support staff. She attends a local college where she

is taking a number of courses.
Shazia has had manic depression (a bipolar illness) for several years. Her episodes of mania and depression are managed at home. Shazia sees a psychiatrist every six months (more frequently if unwell) and a community nurse every month. Both work in the Community Learning Disability Team. Shazia is on a standard CPA and the community nurse is her care coordinator. She has a CPA meeting once a year. Her staff team and care coordinator have developed a system that alerts them to when Shazia's behaviour is becoming manic or depressed.

The staff team have been recording Shazia's behaviour as usual. They have noticed that she is starting to become manic and have called the care coordinator, who has arranged a meeting with the psychiatrist. The psychiatrist increases Shazia's medication but this has little effect. Everyone has become increasingly concerned about Shazia as she has begun to self-harm, she is not sleeping and she has lost considerable weight.

An emergency CPA meeting is held where it is decided that it would be in Shazia's best interests if she were admitted into hospital for a period of assessment and treatment. The care coordinator liaises with the staff of the local mainstream in-patient ward who agree to admit Shazia with the support of the house staff and the Community Learning Disability Team.

The care coordinator discusses going into hospital with Shazia, but Shazia does not agree. Due to the severity of the situation and concerns about possible self-harm, Shazia is assessed under the Mental Health Act (1983)

and admitted into hospital under a section for assessment. The staff team develop an information pack about Shazia to help the ward staff get to know her and meet her needs. The care coordinator arranges for the ward staff to have some training on people with a learning disability in general, communication issues and more specifically about supporting Shazia. The care coordinator, psychiatrist, the house staff and a speech and language therapist jointly deliver the training.

Shazia progresses well on the ward. As she gets better, she agrees to remain on the ward and is taken off the section. A CPA meeting is called to arrange her discharge from the ward. As Shazia has been detained under the Mental Health Act she is discharged under an enhanced CPA. Her needs are reassessed and her care plan is developed to reflect the current situation. A CPA meeting is arranged for two months' time to review progress. The mainstream ward staff agree to provide training to the house staff on supporting people through manic episodes. The team find this very beneficial.

5.7 Joint working with other professionals and agencies

Meeting the mental health needs of people with a learning disability is a multi-agency process, with collaboration across a wide range of people and services. Support staff are a pivotal part of this process, working closely with other professionals.

The role of support staff when engaging with health and social care workers is first and foremost to empower the person with a learning disability. This includes supporting the individual in communicating with professionals and ensuring that the person's point of view and wishes are always at the centre of any discussion or intervention. Information on supporting people with a learning disability in assessments, etc. can be found in Section 6.

Support staff need to be aware of the range of services that are available in the local area for people with mental health needs, what might be appropriate, how they can be accessed and how they operate. Care plans should always be developed in collaboration between the person with a learning disability and the professional and support staff. If the person with a learning disability or any of the staff team have concerns about the appropriateness of an intervention they should raise the issue with their manager, care coordinator and the relevant professional as soon as possible.

People being assessed and/or treated will find that contact with health and social care professionals is often time-limited, so the person with a learning disability and staff team need to make the best use of that time. To ensure all relevant issues are explored it may be helpful at the beginning of the process for the person using the service and staff team to discuss their expectations with the professional. This may involve what the professional expects of the staff team (e.g. implementing care plans, recording information) and also what the person and team expect of the professional (e.g. reports, feedback, confidentiality).

In forging links, communication and consistency are vital in all aspects of the role of support staff. When in contact with professionals, the following may be useful:

- For any meetings, appointments or telephone conversations there should be a main point of contact, such as the person's keyworker.
- The keyworker should be fully prepared before such events. This will include consulting with the person with a learning disability.
- Further supportive information will be gained by taking a team view on the matter to be discussed. This will probably also involve providing a clear and accurate record of relevant information. The type of information professionals will need is discussed in Section 6.
- Outcomes from meetings and appointments should be fed back to the whole staff team and implemented as agreed.
- Staff should support the person to exercise their right to choose appointments and their healthcare.

Records of meetings and reports etc. should also be made available and accessible.

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5.8 Action points for staff to promote joint working

- Involve the person using the service, family, and carers in mapping people's actual experiences of life and services. Use this to identify actions and develop a clear plan for ongoing care that is shared with all services.
- Promote mutual understanding. Support staff can help by understanding what different services do and how to access and refer, setting up systems and processes for interagency working and ensuring that case working across agencies is effective.
- See what protocols already exist for inter-agency working and cross-reference these with the Green Light Toolkit (see Section 3 for further information). Do the protocols describe what actually happens or are there gaps in practice?
- Protocols should cover what each agency does and can offer for the client group; common assessment tools and procedures; agreed care pathways, including referral arrangements, assessments, service provision and arrangements for discharge where appropriate; confidentiality/data sharing; standardised data collection; discharge arrangements for all services and joint training plans and risk assessment.
- Where there are gaps or problems alert your managers and/or arrange a multi-agency meeting to discuss the issues so that each party understands their role and that of other agencies.
- Do a training needs audit within your team and act upon identified needs. Consider reciprocal training between mental health and learning disability services.

- When the joint working as described above is still not able to support a particular individual, there should be a clear pathway for referral to more appropriate agencies.
- An agreed strategy for continuing care is important in minimising relapse and maximising positive outcomes.

The next section describes how staff can help people with a learning disability through the assessment process, which acts as a gateway to a range of support services.

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Section 6: Access to services via an assessment

The first stage in accessing statutory services is through the mental health assessment process.

6.1 What is an assessment?

An assessment is a process which involves two essential components. Firstly, gathering information about an individual (involving the individual in the process) and using the information to develop a clear picture of the person's current level of functioning and, secondly, arriving at a decision concerning the person's state of mental health. Mental health assessments are an ongoing process that take time, but a comprehensive assessment will ultimately lead to an effective intervention package that will improve the person's mental health and quality of life.

Supporting people with a learning disability to prepare for an assessment

> 'I get nervous going to see the doctor. My keyworker talks to me about what is going to happen. We write down what I am going to say.'
> *Person who uses services*

There are some steps that support staff can take to reduce stress and make the experience of an assessment better for people with a learning disability.

- Obtain any accessible information on the services they may be using, e.g. the clinic or GP practice. Read through this with the person as many times as needed and support them to fully understand the information.
- Consider where the best possible place for the assessment to take place is and how long is required. For instance, if an appointment at the clinic is not appropriate (e.g. due to the person's anxiety or behaviour) a home visit might need to be arranged. For complex cases, a longer appointment might be needed or assessment may need to take place over several sessions.
- If the assessment is to be held somewhere that the person is not familiar with, they could visit the location beforehand.
- Explain to the person the reason for the appointment, what will be happening, when it will take place, who will be there and the types of questions that might be asked. Try to make the experience as predictable as possible. (Although for some people, forward planning might make them more anxious, and this depends on the individual. Sometimes it will be appropriate to discuss these issues with the person only a short time before the assessment.)

6.2 How can support staff prepare for the assessment?

Preparation for the assessment involves gathering information and presenting it in an understandable way to the professional. An individual may already have their own Health Action Plan and Person Centred Plan which should both be used during this process. Staff may need to provide information covering the following areas.

Historical information
This includes the early stages of the **person's life**, any known causes of the learning disability or associated developmental disabilities, such as autism. This also covers information about the person's schooling, significant life events, employment, where they have lived, friendships, sexual relationships and services they have used. This information enables the practitioner to better understand the individual, to be aware of areas that may make them vulnerable to developing a mental health problem (vulnerability is more fully discussed in Section 2) and which may need to be taken into account when developing an intervention plan. Certain conditions (e.g. Down's syndrome and Alzheimer's dementia) and situations (e.g. loss and bereavement) are associated with particular mental health problems and will alert the practitioner to consider these possibilities.

Details of the different **family** members, their medical and psychiatric history and the person's relationship with them will also help the practitioner in their assessment. Support staff may not know some of this information,

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but if they do, it may be useful as some conditions tend to persist within families, e.g. mood disorders.

Any information on the person's past **mental health** should also be collated. Include details of previous illnesses, type and place of treatment (home/hospital), how effective treatment was, whether there was compliance with the treatment, any significant life events before the illness and if detention under the Mental Health Act was required.

Similarly, details about **physical health** should be gathered. Ill health can predispose people to mental illness, for example chronic pain is associated with depression. Physical conditions may also mimic mental health problems. For instance, if the thyroid is not functioning properly the person can become forgetful and experience low mood. They may appear to have dementia or depression. People with Down's syndrome are at particular risk of thyroid problems. Urinary tract infections are common in older people with a learning disability. These can lead to confusion, disorientation and psychotic symptoms. Pain may present as challenging behaviour. In these examples treatment would be directed at the underlying medical condition.

Some **medicines** are associated with mental health problems, so the practitioner needs to know about these. For example, some heart tablets predispose people to depression and sometimes confusion. Also, current medication may affect the choice of medicine for the mental health problem, as drugs can interact unfavourably with each other.

Current situation
The professional will want to know about the person's current situation. The staff team should gather the information about what changes have occurred (i.e. both around the person and their functioning), when the changes started and state why these changes are causing concern.

Support staff can also contribute recorded information they have gathered. This could include:

- daily care diary
- sleep, weight, diet charts
- drug charts
- charts of behaviours
- good days, bad days
- essential lifestyle planning, etc.

6.3 **The assessment**

At the assessment the person should be offered the support of someone who knows them well and whom they have confidence in. This could be a relative, advocate, partner, etc.

Inform the mental health professional of any special needs and wishes that the person may have, such as problems with communication, sight, hearing or physical accessibility, or meeting in a particular room.

Occasionally, professionals may direct their questions to support staff and not to the person with a learning

disability, as they may assume that they are unable to understand or communicate. Support staff should do their best to support the person to communicate their thoughts and feelings themselves to the professional. The person's Health Action Plan and Person Centred Plan will help other professionals understand how they can best support the individual.

'Support workers should help us tell the doctor what is wrong. They should help us speak up for ourselves.'
Person who uses services

The assessment process depends on which professional is involved. When a referral is received by the mental health team, the team discuss who is the most appropriate person to carry out the initial assessment. This will depend on a number of factors including considering what seems to be the problem (e.g. if there is challenging behaviour a psychologist may be the most appropriate person) or if someone from the team already knows the person. Often a number of people will need to be involved at some point (e.g. it may be clear from the referral letter that a speech and language assessment would be helpful).

The initial assessment will enable a decision to be made about any immediate interventions needed, and who else the person should see. A person will be identified to coordinate this process. The assessment informs the professionals' view of what the condition is (or in medical terms, the diagnosis), what may have predisposed the person to the condition, triggered it and

is maintaining it (the formulation) and enables them to decide with the individual and others how best to proceed (the treatment or intervention). We shall discuss interventions and treatments in Section 7.

> 'We might need more time to say what we want. It's not easy talking about feelings.'
> *Person who uses services*

The following gives an overview of how an assessment by a **psychiatrist** or **community psychiatric nurse** is carried out.

Whilst gathering information about the person's past and present situation the practitioner will also be assessing their mental state. They will observe the person's dress and demeanour (dishevelled, fidgety, etc.), their mood (relaxed, low, etc.), their thoughts and beliefs (if these are unusual in any way), whether their thinking is muddled or not and if they can concentrate and remember things.

It may be necessary for particular questionnaires to be completed, either at the initial appointment or later.

The practitioner may want to do a physical examination. Blood tests or medical investigations may need to be ordered. They may wish to refer the person to other professionals for an opinion. Sometimes they may recommend further assessment as an in-patient, if the assessment cannot be carried out in the community because of the complexity of the problem or because of unacceptable risk to the safety of the individual or others.

At the end of the initial assessment the practitioner will discuss their findings with the person, and agree a plan with them as to how to proceed. They will seek the person's permission to write a report and agree with them who should receive this. If the person is unable to consent the practitioner will decide on a 'best interests' basis (see Section 3).

6.4 Risk assessment

An integral part of any mental health assessment is the assessment of risk and it is a fundamental part of CPA (see Section 3). It is important to have proper assessment and management of risk. This is not only to protect people with a learning disability and workers but also because this is an area where there is significant ignorance, fear and stigma. Assessment of risk is essential in helping to establish a consistent approach.

Risk assessment enables us to identify the support that someone needs to implement goals set in their Person Centred Plan. It is also key to the protection of the individual, professionals working with them and the wider community and it enables the individual, practitioner and other professionals to work more effectively together and therefore helps to promote engagement. It is also important to bear in mind that people are more likely to pose risk to themselves than to others.

When working with health professionals, support staff must inform them (and their managers) of any risk that they have identified. This may include aggression, self-harm and suicidal ideas or attempts. The professional will work closely with the staff team in assessing the degree of risk, i.e. what is the likelihood of the risk occurring. This may involve the gathering of information and keeping accurate records such as charts of behaviour and incident forms. Then a plan will be developed to minimise the likelihood of the risk occurring. A contingency plan will be put in place in the event of the risk occurring. It is important that the risk assessment looks at the individual rather than generalised risk factors. It is helpful for services to work together to develop protocols that enable a shared approach to risk assessment and management. Risk assessments should not prevent the person from undertaking an activity (unless it is harmful to themselves or others), but should describe what happens and be used to put appropriate support and/or alternative arrangements in place to enable the person to continue to enjoy this aspect of their life.

6.5 Formulation and diagnosis

As discussed above, the assessment process will lead to an understanding of what the condition is and why it has arisen. On the following page is an example of how the assessment process can lead to a diagnosis and formulation, and the role of support staff in the process.

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Case study

June is 52 and has a learning disability. She lives in a supported house with three other women who have a learning disability. June enjoys a wide range of activities at home, and in the community. She attends pottery classes, horse riding and swimming sessions. Her favourite activity at home is cooking. She has no history of mental health problems. Occasionally she will eat inedible objects such as cigarette butts. June has a sister and a brother.

A few months ago June's sister emigrated. Before this happened the team sought the help of speech and language therapists to provide them with accessible information. June's sister and her brother supported her keyworker in explaining what was happening and how they would keep in contact. June's brother gave her lots of reassurance and arranged to see her more regularly over the next few months.

The staff team always spend time with June, chatting to her about a variety of things. However, since her sister emigrated they have planned specific times to talk to her about her sister and her feelings and have supported her in developing a memory book, including photos, etc. She is also regularly supported to send letters and to telephone.

Three months have passed since June's sister emigrated and though they have followed a comprehensive care plan since then, the staff are quite concerned about June. They have always kept good records on the

health, behaviour and daily activities of the people living in the house. Over the last month they have noticed that June has had trouble sleeping. The night staff have often found her wandering around. According to her activity chart she has not been joining in the house cooking and other activities as she normally does and the pottery class teacher has mentioned that June is finding it hard to concentrate. June's weight chart notes that she has gradually lost four pounds over the last two months and with hindsight the staff have discussed how her appetite has decreased. June's brother has also noted that she is far less communicative when she visits. Charts indicate that incidents of eating cigarette butts have increased.

June's keyworker discusses the above with June, telling her that her brother and the team are worried about her. The keyworker suggests that June might like to visit her GP to see if they could suggest anything, June agrees. The GP does a thorough health check but can find nothing problematic with her physical health. Considering recent events in June's life and the changes in behaviour, with June's consent she refers her to the psychiatrist at the Community Learning Disability Team (CLDT) for a mental health assessment.

As June tends to become anxious in new situations her brother and keyworker support her to visit the CLDT building several times before the appointment. The keyworker spends time with June explaining to her what will happen in the meeting. At the assessment meeting

June agrees for her keyworker to explain to the psychiatrist exactly why the team are concerned and to give him an idea of what June is normally like and what has changed recently (i.e. sister emigrating and changes in behaviour). Copies of charts (i.e. sleep, weight, activities, record of eating butts) are given to the psychiatrist.

The psychiatrist notes that June seems subdued and withdrawn. She sits passively and looks sad. She answers some of his questions, but is unable to describe how she is feeling or if anything is troubling her. She looks to the member of staff to answer for her, despite being encouraged to answer herself. She stares blankly when asked about her sister.

From the history and June's presentation he decides she is depressed and that this was triggered by her recent loss.

We will return to this case again in the next section when interventions and treatment are discussed.

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Section 7: Interventions and treatment

This section describes the role of mental health interventions and treatments, the main types that are available to people with a learning disability and the role of support staff in implementing them.

7.1 Does the person have to agree to have an intervention?

People have the right to make their own decisions and to be supported to make those decisions. However, the law allows treatment to be given without consent in three instances:

- If a person lacks capacity to make a decision about an intervention, staff should take all the steps needed to help the person understand the information relating to that decision. If the person lacks capacity to make this decision then it can be made for them, as long as it is in their best interests. This is explained in detail in Section 3 in reference to the Mental Capacity Act. The lead professional in relation to the particular treatment being offered is responsible for deciding if the person has capacity to give consent. For example, with medication it would be the prescriber (e.g. psychiatrist or GP); with other therapies such as psychological interventions it is the lead therapist (e.g. psychologist).
- If there is an immediate danger to the patient or someone else.
- Medical treatment for mental health problems can be given to a person who is detained under the Mental Health Act (1983). (See Section 3 for further information.)

'We have the right to say yes or no.'
Person who uses services

7.2 What is the role of interventions and treatment?

Interventions and treatment for mental health problems are based on the outcome of the assessment. They aim to:
- reduce signs and symptoms of mental health problems
- reduce distress to the individual
- increase social inclusion
- improve the person's quality of life
- reduce the likelihood of relapse. The assessment leads to an understanding of what made the individual vulnerable to developing a mental health problem. Part of the intervention plan may seek to address some of these vulnerabilities (e.g. by improving self-esteem, changing medicines). Similarly, issues that triggered or are maintaining the person's problem should be addressed, otherwise they may relapse. Information on improving the person's protection against mental health problems is discussed in Section 4.

A range of interventions should be developed that address the social, psychological and biological needs of the person. Intervention packages are likely to be multi-disciplinary, with input from a number of health and social care professionals. A care coordinator ensures that this happens in a planned manner (see the information on CPA in Section 3). Intervention packages should be regularly reviewed, evaluated and modified as required.

Most interventions occur in the community. Sometimes they occur in specialist settings. These include hospitals as well as specialist community settings for people with challenging needs.

7.3 What different types of interventions and treatment are there?

The three main types of interventions for mental health problems are:
- social interventions
- psychological interventions
- biological interventions.

Social and psychological interventions are important, either on their own or in conjunction with medication, as they can control the symptoms of a mental health problem. Which intervention is chosen depends on the person's choice, their mental health assessment, what the condition is, the availability of particular interventions (for instance there may be a waiting list for certain types of psychological treatments), and the presence of any contra-indications (e.g. some medicines would be best avoided if a person has a heart condition).

'We have the right to have the same treatment as everyone else. We should be given information about treatments.'
Person who uses services

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For example, returning to June who was discussed in Section 6:

The psychiatrist discusses his ideas for an intervention plan with June and her keyworker. He compliments the staff team on the support they have given June around recent events and thinks this should continue. He suggests that June might find psychological and medical treatments beneficial as well, as her mood has not improved over recent months.

The psychiatrist recommends that June be assessed for cognitive behaviour therapy (explained on page 46). However, he believes that she is probably too depressed at present to engage in and benefit from talking therapies. With June's permission he wants to discuss this with his psychology colleagues and in the meantime asks June to take anti-depressants. He believes she needs time to think about this plan, so he gives her some information on the medicine and talking therapies written in an accessible format for her to consider with the staff. He arranges to see her in a week to discuss the plan and recommends that the staff continue with their care plan at home, but taking everything at a pace June wants.

June returns to the clinic a week later with her brother and keyworker. She has spent considerable time with her brother and the staff looking over the information and gives her consent to the treatment plan. June's brother tells the psychiatrist that he is worried that June will be on the medication for years. The psychiatrist says that it would be until June gets better and this is

generally six–nine months for most people and assures him that the medication will be reviewed every six weeks. The psychiatrist prescribes an anti-depressant with minimal side effects, which he explains in detail. The keyworker suggests that she develops a care plan for the medication ensuring that the staff team look out for the side effects and that June is regularly consulted about taking the medication and reviews the information the psychiatrist has given her. June is then referred to the psychology service and allocated a community psychiatric nurse (CPN). June is placed on standard CPA and the CPN will be her care coordinator.

Six weeks later June's mood has gradually improved. She has recently seen a psychologist who thinks June would benefit from cognitive behaviour therapy. June meets with a psychologist over 14 sessions. The psychologist teaches June some skills in recognising her emotions and identifying some coping strategies. The psychologist also supports June's brother and staff team on building on the work they had already done with June. The CPN visits June at home every three weeks to review how she is feeling and to discuss any issues with the medication.

It's been seven months since June visited her GP and she is back to her normal self. Over this time the staff team have slowly supported June back into her activities. At a review June tells everyone how well she feels. The cognitive behaviour therapy has worked well and June has been using her coping strategies when she feels upset. The psychiatrist suggests that June should now come off the antidepressants, to which June

agrees. These are gradually stopped over a four-week period. The staff team develop a care plan that will alert them if June is becoming depressed again.

Below is an overview of the different types of mental health interventions.

7.4 Social interventions

Social interventions are often directed at the factors that made the person vulnerable to the mental health problem. They include addressing issues such as accommodation, finances, employment and daytime activity and social relationships. Social interventions are where support staff can make a big impact in improving the person's mental health and quality of life. Many social interventions are also the protective factors that can help a person stay mentally well (these are discussed in more detail in Section 4). Support staff should discuss these factors with the care coordinator to see which should be implemented.

An important aspect of social interventions is people's approach to those who have experienced mental health problems.

7.5 What can you do if someone is having hallucinations or delusions?

Hallucinations and delusions can be quite frightening and unsettling. Supporting people with these symptoms can be stressful. In these situations support staff should ask professionals such as the psychiatrist and/or psychologist how to respond to the individual and this can be part of the care plan.

Some general guidelines on how to respond include:

- Always remember that the person's experiences are very real to them, however unbelievable they may seem to others.
- Acknowledge the person's experiences are real to them, but do not agree with them (if they are definitely untrue). Some feelings of paranoia might be justified, for example if the person is being bullied.
- Do not make fun of the individual, criticise them or argue with them.
- If the person has coping strategies such as listening to music or talking into a mobile phone when they hear voices, encourage them to use these strategies.

Try to get the person to think about something else, for example by talking about a subject they like or by starting a new activity.

7.6 People with mental health problems and aggression

I've heard that people with mental health problems are aggressive: how can I tell if they are going to be aggressive?

People with mental health problems may become aggressive, for example as a result of hallucinations or delusions. Aggression is uncommon, and is usually aimed at themselves (i.e. self-harm). However in certain circumstances, such as when experiencing frightening psychotic symptoms, aggression to others may occur. A risk assessment is part of all CPA care plans (see Section 3). The care coordinator, together with the individual and those supporting them, develops this. It sets out the risks, how to reduce the likelihood of them occurring, how to recognise the warning signs of the behaviour occurring and how to react if it does occur.

There are some general signs that can warn us that someone is agitated and may become aggressive. These include:
- pacing up and down
- breathing rate increased and sweating more than normal
- staring at other people or avoiding eye contact
- disagreeing with those around them
- rigid body stance and muscular tension
- changes in level of communication – becoming quieter or louder
- mumbling to self or incoherence
- lack of concentration.

Staff should follow the care plan if the person is showing signs that they may become aggressive. The following general points may be helpful.

Speaking and listening
- Talk clearly and slowly
- Keep your voice at a normal tone, do not shout or raise your voice
- Listen carefully to what the person says
- Give the person time
- Ask them to explain what has upset them
- Acknowledge what the person says, but try not to agree or disagree with them
- Reassure them if they are worried
- Do not blame the person for anything and avoid blaming others
- Do not make promises that cannot be kept
- Be non-judgemental and non-critical
- Use non-threatening language
- Appear calm, self-controlled and confident.

Body language
- Act in a calm manner, even though you may not feel calm
- Try to look relaxed
- Do not fold your arms, point or wave your hands around
- Try to keep your hands at your side
- Stay at the same level as the person – if they are sitting, you should sit, if they are standing, you should stand
- Do not stand right in front of the person.

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Eye contact
- Make eye contact (but remember some people, such as those with autism, do not like this)
- Try to make natural eye contact – most people occasionally glance away when they are talking to someone
- Do not stare at the person.

Space
- Do not invade the individual's personal space
- Keep a safe distance between yourself and the person
- Though the situation might not be at crisis point, you should remain aware of the following:
  – Do not back yourself into a corner
  – Always know where your nearest exit is and keep yourself between the person and the exit.

Other people
- Make sure other staff are aware of the situation
- Ensure the safety of yourself and others
- Make sure you are not intimidating the person by surrounding them
- Ask other staff members to support other people present.

Environment
- Consider whether the environment can be changed to prevent the situation getting worse
- Ensure the privacy, respect and dignity of the person
- Be aware of potential hazards, in case the situation escalates.

People often feel embarrassed about having mental health problems or regret how they behaved when they were unwell. They may have lost their confidence and may also be anxious about the possibility of relapsing. Those who have experienced an episode of schizophrenia may be experiencing negative symptoms such as apathy and a lack of motivation. These can often be misinterpreted as laziness and staff can make moral judgments about the person. This may lead support staff to inadvertently put pressure on the individual and make critical comments. This increases the likelihood of the person relapsing. Support staff should educate themselves about the person's mental health problem, adopt a non-judgemental attitude to the person and support the person back into their routine at a pace that suits the individual.

7.7 Psychological interventions

There is a wide range of psychological therapies that can help people with mental health problems. All forms of psychological interventions are based upon talking and listening and to varying degrees include some kind of activity. They include the following.

Behaviour therapy
This is based on the theory that behaviour is learnt through reinforcement (such as being rewarded when a certain action is performed). This is used more often with people who have great difficulty in expressing their inner thoughts and feelings.

Behaviour therapy is most commonly used with those who exhibit challenging behaviour. It can be used to teach individuals new, more appropriate skills and develop their anger management techniques. It is also used with people who are experiencing anxiety, for example teaching them relaxation exercises and slowly desensitising people to situations or objects that they find frightening.

Cognitive behaviour therapy
Cognitive behaviour therapy (CBT) is a structured approach of relatively short duration (10–20 sessions). It helps people to understand that their behaviour and emotions are influenced by their cognitions (i.e. their thoughts and beliefs). CBT encourages the person to recognise negative cognitions and situations that may trigger them and develop new ways of coping with problems. CBT also attempts to get the person to identify deep-rooted negative assumptions they have about themselves and to challenge them. Therapy usually occurs for a set time (e.g. one hour) every week over a predetermined period (e.g.12 weeks). The person may be set homework such as keeping a mood diary.

CBT is most commonly used in treating depression and anxiety. It is sometimes used to help with some of the symptoms of schizophrenia. For example, it could be used to help someone who is experiencing unwanted thoughts. The person might be taught self-distraction techniques, like focusing on something else every time the thought enters their head. This could include thinking about something positive, counting or concentrating on

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something in the immediate environment. Someone who hears voices might be encouraged to listen to their Walkman or wear earplugs when the voices are talking.

Sometimes when people have mental health problems they may focus on negative thoughts. For example, a person with a learning disability who is depressed may have a belief that they are worthless. The therapist could teach the person to identify when they are most likely to think these thoughts (e.g. when bored or lonely) and support them to reduce the opportunities for these thoughts to occur.

People with depression often have low self-esteem and may misinterpret situations. For example, Jim has a learning disability and attends college. He arranges to meet his friends in the pub after college. When he arrives he sees his friends across the room and waves at them but they do not wave back. Jim feels very upset and goes home. Due to his depression and low self-esteem Jim thinks to himself 'I shouldn't have come, they don't like me, I don't deserve to have friends'. The therapist could help Jim overcome these negative feelings by supporting him to explore alternative explanations, for example, they did not see him or the room was too smoky, etc.

> 'We should have access to counsellors and psychologists.'
> *Person who uses services*

Counselling

Counselling offers individuals opportunities to privately discuss their problems with someone who is separate from their everyday life. The counsellor listens attentively to the person, who is encouraged to express their thoughts, feelings and experiences. The counsellor supports the person to develop his or her own solutions. Counselling is often used with people with a learning disability when they have experienced loss, such as bereavement.

Psychodynamic psychotherapy

Psychodynamic psychotherapy is based on the theory that people have an unconscious mind where painful feelings are kept. The therapist helps the person realise their true feelings and to connect past experiences with present behaviours and change these behaviours. This therapy is more suitable for people who can express their feelings to others and are able to recall events and feelings from the past.

Is everything that is said between the therapist and the individual confidential?

The success of all interventions is built on trust between the individual and the therapist. At the beginning of therapy the therapist will discuss confidentiality and establish to whom information can be disclosed. This may or may not include support staff. The therapist has a duty of care to maintain confidentiality but also has a duty to report any discussion that may put the person or others at risk, such as suicidal ideas, intent to commit violence or disclosure of abuse. Support staff should not directly

question the individual as to what was discussed in therapy. Support staff may receive reports and feedback from the therapist on progress, but these are likely to be written in general terms and will not contain specific details.

What is the role of support staff with psychological interventions?

Staff should ensure that the individual is aware of when and where therapy sessions are and support them in accessing them. The person may be given homework to complete in between sessions, especially if they are having cognitive behaviour therapy. This may include keeping mood, thought or emotion diaries. Staff should support them with their homework. Individuals may become upset after a therapy session, as difficult issues may have been discussed. Staff should provide support and empathy at these times, but should not directly ask the person about what happened in the session. This should only be discussed if the person raises the topic themselves.

7.8 Biological interventions

The main type of biological intervention is the use of prescribed medication. As with all interventions for mental health, it is best used in an intervention package and not as a stand-alone treatment.

In the past, medication has been too heavily relied on for people with a learning disability and mental health problems. This has been partly due to the lack of

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psychological therapies available and people living in long-stay institutions where staffing levels were very poor and little interaction occurred. Recently things have started to change. People with a learning disability have increased access to a wider range of interventions, there is increased knowledge about mental health problems and medication and there are national guidelines on the prescribing of medication for mental health.

> 'We should be asked if we want to take medication. We have a right to say no.'
> *Person who uses services*

What are the main types of medication and do they have any side effects?
Medicines have more than one name. One is the chemical or generic name and the others are trade names (given by the companies that make them). They come in different forms – tablets, capsules, liquids or injections.

The person may need tests before starting medication to ensure they are fit enough to take it and as a base line against which subsequent results can be compared (e.g. blood tests and ECG, i.e. heart recording).

All medicines have side effects. These should be monitored, to ensure that the benefits outweigh any unwanted side effects. Some medicines will require regular blood tests (for instance clozapine and lithium). The person should be given information about their medicine so that they understand what it is for, how to take it, what problems it may cause, etc.

The main types of medication for mental health problems are discussed in the appendix.

> 'We need information about medication. We need to know why we should take it, how and when we should take it, about the side effects and how it will help us.'
> *Person who uses services*

What is the role of support staff with medication?
Each service, whether residential, day or outreach, should have a policy on the administration and storage of medication. Staff have a duty of care to correctly follow these policies. When someone is prescribed medication, support staff should ensure that the person themselves (as much as possible) and the staff team are made aware of the following by the doctor or nurse:

- The chemical and trade name of the medication
- What the medication is for
- What form it comes in (e.g. tablet, liquid, etc.)
- How the medication is administered (e.g. oral, injection, etc.)
- The dose to be given
- How and when to take the medication
- How long the medication should be taken for
- How it will be helpful for the person
- The possible side effects and how to recognise them
- What to do if side effects occur
- When the medication will be reviewed
- If they have any information for the individual and staff to take away.

Staff also have an ongoing responsibility to informally monitor the effects of the medication on the individual. Before each medication review the staff should consider with the individual whether the medication has helped, if they have experienced any side effects and if it has been taken as it was recommended. Together, they can decide what they want to say at the review and what questions they want to ask.

What should we do if someone refuses medication?
If a person refuses his/her medication, staff should try again a little later. If refusal of medication continues, staff should contact the doctor who prescribed it as soon as possible, as the person may be vulnerable to having a relapse or be likely to develop ill health from suddenly stopping the medicine. Support staff should not hide medication in an individual's food or conceal it in any other way unless the doctor that prescribed it has agreed this method (this would only happen exceptionally and after consultation), otherwise staff could be charged with assault.

People with a learning disability have the right to refuse medication like anyone else. However if, after assessment, they are found to lack the capacity to make the decision they can be given the medication, if it is in their best interests. This area has been clarified in law through the Mental Capacity Act (see Section 3) which defines 'best interests'.

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Medications and challenging behaviours

Why are some medications for mental health problems used for people with challenging behaviours?

Support staff may find that some people they support may be on antipsychotic or mood stabilising medication, even though they do not have a diagnosis of a mental health problem. This might be because their behaviour is described as challenging. Good practice dictates that staff and professionals should try to find out why the person's behaviour is challenging and support them to find alternative ways to behave. This can take time and medication is sometimes used in the short term to help control specific symptoms, (e.g. anxiety or restlessness) rather than to treat a mental disorder (e.g. depression or schizophrenia). Very occasionally a person's behaviour might be challenging over a long period of time and it may be very difficult to unravel why the person is behaving in such a way; in these instances medication might be used in the long term.

Whether it is in the short or long term, the use of medication for challenging behaviour should always be implemented as part of the person's overall care plan in discussion with the individual and the multi-disciplinary team. It should be regularly reviewed and not seen as a permanent solution.

7.9 Other interventions

Are there any other interventions that can help?

There are many other interventions that have been found to help people with mental health problems, such as art, drama and music therapy. The local mental health NHS Trust may provide such therapies or the local occupational therapy service may know how they can be accessed.

The implementation of these therapies must be agreed with the multi-disciplinary team. They are part of the person's care package and as such should be considered through the CPA process. Most organisations will have policies on the use of complementary therapies and staff must check before supporting someone to access them.

Information about these therapies can be found at:

British Association of Art Therapists
www.baat.org

British Association of Drama Therapists
www.badth.org.uk

Nordoff-Robbins Music Therapy UK
www.nordoff-robbins.org.uk

There are a number of **complementary therapies** such as aromatherapy, acupuncture, reflexology, etc., that can be helpful to people with mental health problems. Information can be found at:

Institute for Complementary Medicine
www.i-c-m.org.uk

Part C of this document provides some good practice guidance for support staff which can be used in your day-to-day work, further information sources and an appendix of prescribed medicines.

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Part C:
Good practice summary and further information

8

9

App

Section 8: Good practice recommendations

These recommendations summarise the good practice described throughout the guide.

- Be proactive in your approach to mental health. Develop care plans that promote positive mental health and reduce vulnerability factors for all people with a learning disability, including those who have never previously experienced mental health problems.

- Be aware that changes in behaviour and functioning can indicate the presence of a mental health problem. You should identify, record and discuss these changes amongst the team.

- Changes in routine and any transitions between services should be carefully planned and managed with the full involvement of the individual.

- You should be consistent in implementing care plans and guidelines. If you have any concerns these should be immediately reported to the care coordinator and their manager.

- People with a learning disability have the same rights as any other citizen. This includes making decisions for themselves and being supported to do so. In some instances people may lack the capacity to make decisions for themselves. In these instances you should discuss the issue with their manager, with special consideration of the implications of the Mental Capacity Act (see Section 3).

- Familiarise yourself with the Green Light Toolkit (see Section 3) which sets out good practice for services in supporting people with mental health problems.

- It is important to also consider social and psychological interventions, either on their own or in conjunction with medication, as they can control the symptoms of a mental health problem.

- You should contribute to the CPA process (see Section 3) by supporting the person with a learning disability to express their point of view and to attend meetings. Inform the care coordinator of any problems that arise and discuss any proposed changes to the care plan before implementing them.

- It is important to be aware of other services and ensure collaboration and a multi-agency approach to supporting people with a learning disability.

- You can contribute to the mental health assessment by supporting the individual through the process and helping them communicate with clinicians. Provide clinicians with historical information and current information such as charts, records and care plans.

- In cases where individuals are taking medication, you should be aware of the service's medication policy. You should be aware of, monitor and report any side effects of medication.

- Individuals who are having psychological treatment should be supported by staff. This includes respecting their privacy and supporting them to complete tasks set by the therapist.

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Section 9: References and resources

This section includes:

- References and further reading for support staff on mental health issues for people with a learning disability
- Resources for developing skills and supporting people with a learning disability
- Government documents
- Useful organisations
  – Learning disability email networks
  – Learning disability organisations
  – Mental health organisations
  – Other useful organisations
  – Useful websites

9.1 References and further reading

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9.2 Resources for support staff

Depression in People with Learning Disability
Royal College of Psychiatrists
www.rcpsych.ac.uk

Down's Syndrome and Dementia Resource
Dodd, K., Turk, V. and Christmas, M. (2002)
British Institute of Learning Disabilities
www.bild.org.uk

Learning Disability and Mental Health
Royal College of Psychiatrists
www.rcpsych.ac.uk

Meeting the Emotional Needs of Young People with Learning Disabilities
Wertheimer, A., Hewitt, A. and Morgan, H. (2003)
Foundation for People with Learning Disabilities
www.learningdisabilities.org.uk

Mental Health in Learning Disabilities: A Training Resource
Edited by Holt, G., Hardy, S. and Bouras, N. (2005)
Pavilion Publishing
www.pavpub.com

Understanding Depression in People with Learning Disabilities
Hollins, S. and Curran, J. (1997)
Pavilion Publishing
www.pavpub.com

9.3 Resources for supporting people with a learning disability

Accessible Information about Mental Health Medication
(Series of leaflets using pictures and simple English to describe 18 different types of psychotropic medication)

Forster, M., Wilkie, B. Strydom, A. Edwards, C. and Hall, I.
The Elfrida Society
www.elfrida.com

All About Feeling Down
(Accessible booklet)
Townsley, R. and Goodwin, J.
Foundation for People with Learning Disabilities
www.learningdisabilities.org.uk

Books Beyond Words
(Series of picture books that provide information and address the emotional aspects of different events such as bereavement, going into hospital, being a victim of crime and feeling depressed)
Various authors
Royal College of Psychiatrists and Gaskell Publishing
www.rcpsych.ac.uk

Coming For A Drink?
(Accessible booklet)
Band, R.
The Elfrida Society
www.elfrida.com

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Coping with Loss
(Accessible leaflet)
Scottish Down's Syndrome
Association
www.dsscotland.org.uk

Coping with Stress
(Accessible booklet)
British Institute of Learning
Disabilities
www.bild.org.uk

Depression
(Accessible booklet)
Change
www.changepeople.co.uk

Drug Pack
(Accessible information pack)
Forster, M.
The Elfrida Society
www.elfrida.com

*Lets Talk About Death: A booklet
about death and funerals for
people who have a learning
disability*
(Accessible booklet)
Watchman, K.
Scottish Down's Syndrome
Association
www.dsscotland.org.uk

Thumbs Up!
(A training pack on assertiveness
skills for people with learning
disabilities)
Bell, D. Pavilion Publishing
www.pavpub.com

9.4 Government documents

*Valuing People: A New Strategy
for Learning Disability for the
Twenty-first Century*
Department of Health (2001)
Available at
www.valuingpeople.gov.uk

*National Service Framework
for Mental Health*
Department of Health (1999)
Available at
www.dh.gov.uk

*Green Light: How good are your
mental health services for people
with learning disabilities?*
Foundation for People with
Learning Disabilities, Valuing
People Support Team and
National Institute for Mental
Health in England (2004)

Available from
www.learningdisabilities.org.uk
and www.valuingpeople.gov.uk

*Effective Care Co-ordination in
Mental Health Services:
Modernising the Care Programme
Approach*
Department of Health (1999)
Available from
www.dh.gov.uk

*Mental Health and Social
Exclusion*
Social Exclusion Unit (2004)
Available from
www.socialexclusionunit.gov.uk

Mental Capacity Act
Department of Constitutional
Affairs (2005)
Available from
www.dca.gov.uk

Mental Health Act
Department of Health (1983)
Available from
www.dh.gov.uk

Mental Health Bill
Department of Health (2004)
Available from
www.dh.gov.uk

9.5 Useful organisations

Learning disability email networks

Choice Forum
An email network for anyone
interested in the improving the
quality of life of people with a
learning disability.
Free to join, go to
www.choiceforum.org

**Mental Health in Learning
Disabilities Network**
An email network for anyone
interested in the mental health
needs of people with a learning
disability. Free to join, go to:
www.estiacentre.org

**UK Health and Learning
Disabilities Network**
An email network open to
anyone with an interest in the
health needs of people with a
learning disability.
Free to join, go to:
www.ldhealthnetwork.org.uk

Learning disability organisations

**Association for Real Change
(ARC)**
ARC House
Marsden Street
Chesterfield
Derbyshire S40 1JY
Tel: 01246 555043
Web: www.arcuk.org.uk
(Organisation that provides
research and training on a wide
range of issues affecting people
with a learning disability)

**British Institute of Learning
Disabilities (BILD)**
Campion House
Green Street
Kidderminster
Worcestershire DY10 1JL
Tel: 01562 723010
Fax: 01562 723029
Web: www.bild.org.uk
(Organisation that provides
research and training on a wide
range of issues affecting people
with a learning disability)

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Estia Centre
66 Snowsfields
London SE1 3SS
Tel: 020 7378 3217/8
Fax: 020 7378 3223
Email: estia@kcl.ac.uk
Web: www.estiacentre.org
(Organisation that specialises
in the mental health needs of
people with a learning disability.
Provides training, research and
development)

Elfrida Society
34 Islington Park Street
London N1 1PX
Tel: 020 7359 7443
Email: elfrida@elfrida.com
Web: www.elfrida.com
(Organisation that researches
better ways of supporting people
with a learning disability. Provides
a wide range of accessible
information on health issues.)

**Foundation for People
with Learning Disabilities**
9th Floor
Sea Containers House
20 Upper Ground
London SE1 9QB
Tel: 020 7803 1100
Fax: 020 7803 1111

Email: fpld@fpld.org.uk
Web:
www.learningdisabilities.org.uk
(National organisation that
promotes the rights, quality
of life and opportunities for
people with a learning disability
through research, development
and influencing policy)

Mencap
123 Golden Lane
London EC1Y 0RT
Tel: 020 7454 0454
Fax: 020 7696 5540
Email:
information@mencap.org.uk
Web: www.mencap.org.uk
(National organisation that fights
for equal rights and greater
opportunities for people with a
learning disability)

National Development Team
Hill View Business Park
Old Ipswich Road
Ipswich IP6 0AJ
Tel: 01473 836440
Fax: 01473 836441
Email: office@ndt.org.uk
Web: www.ndt.org.uk
(Organisation that looks to
improve policies, services and

opportunities for people who
are disadvantaged, including
people with a learning disability)

Nora Fry Research Centre
3 Priory Road
Bristol BS8 1TX
Tel: 0117 331 0987
Fax: 0117 331 0978
Web:
www.bris.ac.uk/Depts/NorahFry
(Organisation whose interests are
the evaluation and development
of services for people with a
learning disability)

Pavilion Publishing
Richmond House
Richmond Road
Brighton
East Sussex BN2 3RL
Tel: 0870 890 1080
Fax: 01273 625 526
Email: info@pavpub.com
Web: www.pavpub.com
(Organisation that provides
training materials and
conferences on health and
social care, including people
with a learning disability)

Respond
3rd Floor
24–32 Stephenson Way
London NW1 2HD
Tel: 020 7383 0700
Fax: 020 7387 1222
Helpline: 0808 808 0700
E-mail: admin@respond.org.uk
Web: www.respond.org.uk
(Organisation that provides a
range of services to victims and
perpetrators of sexual abuse
who have learning disabilities,
and training and support to those
working with them)

**Scottish Consortium for
Learning Disabilities**
The Adelphi Centre, Room 16
12 Commercial Road
Glasgow G5 0PQ
Tel: 0141 418 5420
Fax: 0141 429 1142
Email: administrator@scld.org.uk
Web: www.scld.org.uk
(Organisation made up of 13
partner organisations that offer
advice, support and consultancy
to services around Scottish policy
on learning disability)

Tizard Centre
University of Kent at Canterbury
Canterbury CT2 7LZ
Tel: 01227 763674
Fax: 01227 763674
Email: tizard-info@kent.ac.uk
Web: www.kent.ac.uk/tizard
(Organisation that provides
research and development in
community care, especially for
people with a learning disability
and challenging behaviour)

Turning Point
New Loom House
101 Backchurch Lane
London E1 1LU
Tel: 020 7702 2300
Email: info@turning-point.co.uk
Web: www.turning-point.co.uk
(Organisation that provides a
range of residential, outreach and
day opportunities for people with
a learning disability. Also provides
services to people with mental
health problems and substance
misuse.)

**Welsh Centre for Learning
Disabilities**
Meridian Court
North Road
Cardiff CF14 3BG

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Tel: 029 2069 1795
Fax: 029 2061 0812
Web:
www.cardiff.ac.uk/medicine/
psychological_medicine/researc
h/welsh_centre_learning_disabi
lities
(Organisation that provides
research, development and
training into the well-being of
people with a learning disability)

Mental health organisations

Alzheimer's Society
Gordon House
10 Greencoat Place
London SW1P 1PH
Tel: 020 7306 0606
Fax: 020 7306 0808
Email: enquiries@alzheimers.org.uk
Web: www.alzheimers.org.uk
(Organisation that provides care
and research for people with
dementia, their families and
carers)

Mental Health Foundation
9th Floor
Sea Containers House
20 Upper Ground
London SE1 9QB
Tel: 020 7803 1100

Fax: 020 7803 1111
Email: mhf@mhf.org.uk
Web: www.mentalhealth.org.uk
(Organisation that provides
research and development and
influences policy to help people
survive, recover from and prevent
mental health problems)

Mind
15–19 Broadway
London E15 4BQ
Tel: 020 8519 2122
Fax: 020 8522 1725
Email: contact@mind.org.uk
Web: www.mind.org.uk
(Organisation that works to
create a better life for people
with mental health problems
through research, development
and influencing policy)

Rethink Severe Mental Illness
30 Tabernacle Street
London EC2A 4DD
Tel: 0845 456 0455
Fax: 020 7330 9102
Email: info@rethink.org
Web: www.rethink.org
(Organisation providing research,
development and training to help
people recover from severe
mental illness)

**The Sainsbury Centre
for Mental Health**
134–138 Borough High Street
London SE1 1LB
Tel: 020 7827 8300
Fax: 020 7403 9482
Email: pr@scmh.org.uk
Web: www.scmh.org.uk
(Organisation that provides
training, research and
development to improve the
quality of life for people with
severe mental health problems)

SANE
1st Floor, Cityside House
40 Adler Street
London E1 1EE
Tel: 020 7375 1002
Fax: 020 7375 2162
Email: london@sane.org.uk
Web: www.sane.org.uk
(Organisation that provides
research and support for people
with mental health problems)

**Scottish Development Centre
for Mental Health**
17a Graham Street
Edinburgh EH6 5QN
Tel: 0131 555 5959
Fax: 0131 555 0285
Email: sdc@sdcmh.org.uk

Web: www.sdcmh.org.uk
(Organisation that undertakes
research and development across
Scotland to support improvement
in mental health and well-being)

**Wales Centre for Mental
Health Services Development**
Business School
University of Glamorgan
Trefforest
Pontypridd
South Wales CF37 1DL
Tel: 01443 482935
Fax: 01443 483558
Email: cjones19@glam.ac.uk
Web: www.walescfmhsd.org.uk
(Organisation that supports
services in development of
effective service delivery to people
with mental health problems)

Other useful organisations

Down's Syndrome Association
Langdon Down Centre
2a Langdon Park
Teddington TW11 9PS
Tel: 0845 230 0372
Fax: 0845 230 0373
Email: info@downs-
syndrome.org.uk
Web: www.dsa-uk.com

Epilepsy Action
New Anstey House
Gate Way Drive, Yeadon
Leeds LS19 7XY
Tel: 0113 210 8800
Fax: 0113 391 0300
Email: epilepsy@epilepsy.org.uk
Web: www.epilepsy.org.uk

The Fragile X Society
Rood End House
6 Stortford Road, Great Dunmow
Essex CM6 1DA
Tel: 01371 875100
Email: info@fragilex.org.uk
Web: www.fragilex.org.uk

National Autistic Society
393 City Road
London EC1V 1NG
Tel: 020 7833 2299
Fax: 020 7833 9666
Email: nas@nas.org.uk
Web: www.nas.org.uk

Prader-Willi Association UK
125a London Road
Derby DE1 2QQ
Tel: 01322 365676
Fax: 01322 360401
Email: admin@pwsa-
uk.demon.co.uk
Web: www.pwsa.co.uk

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Royal National Institute for the Blind
105 Judd Street
London WC1H 9NE
Tel: 020 7388 1266
Fax: 020 7388 2034
Email: helpline@rnib.org.uk
Web: www.rnib.org.uk

Royal National Institute for the Deaf (RNID)
19–23 Featherstone Street
London EC1Y 8SL
Tel: 0808 808 0123
Fax: 0808 808 9000
Email: information@rnid.org.uk
Web: www.rnid.org.uk

Useful websites

Ask Mencap
Provides lots of downloadable information on issues facing people with a learning disability and their carers, including mental health.
www.askmencap.org.uk

Challenging Behaviour Foundation
Provides guidance and information on supporting people with challenging behaviour,

including fact sheets.
www.thecbf.org.uk

Defeat Depression
Provides a wealth of information on depression and associated issues.
www.depression.org.uk

Easy Info (how to make information accessible)
Provides guidance on how to make information accessible.
www.easyinfo.org.uk

Eating Disorders Association
Provides downloadable information on a range of eating disorders and associated issues.
www.edauk.com

Intellectual Disability Health Information
Provides a wealth of information on the health needs of people with a learning disability, including mental health.
www.intellectualdisability.info

Learning Disability Awards Framework (LDAF)
Website offering information on LDAF induction and certificates.

www.ldaf.org.uk

Learning Disabilities UK
Information for staff on issues concerning people with a learning disability.
www.learningdisabilitiesuk.org.uk

Manic Depression Fellowship
Provides downloadable information on manic depression (bipolar disorder) and associated issues.
www.mdf.org.uk

Mental Health Act Commission
Provides a range of information leaflets on the Mental Health Act (1983) for England and Wales.
www.mhac.org.uk

Mental Health Care
Provides a wealth of information on a range of mental health problems and their treatment.
www.mentalhealthcare.org.uk

Mentality
Provides information on promoting positive mental health.
www.mentality.org.uk

National Association for the Dually Diagnosed
A USA organisation dedicated to the mental health needs of people with a learning disability.
www.thenadd.org

National Attention Deficit Disorder Information and Support Service (ADDISS)
Provides information on Attention Deficit Disorder.
www.addiss.co.uk

National Institute for Mental Health in England (NIMHE)
Organisation that supports services both statutory and private/voluntary to implement government policy on mental health.
www.nimhe.org.uk

People First
A national self-advocacy organisation run by people with learning difficulties for people with learning difficulties.
www.peoplefirstltd.com

Royal College of Psychiatrists
An organisation for psychiatrists which also provides a number of

leaflets on mental health issues for people with a learning disability.
www.rcpsych.ac.uk

Scope
An organisation that promotes equal rights and improved quality of life for disabled people, especially those with cerebral palsy.
www.scope.org.uk

UK Medicines Information
Provides information on licensed medication in the UK.
www.ukmi.nhs.uk

Valuing People Support Team
Government agency that supports the implementation of Valuing People. Provides many resources, including for the mental health needs of people with a learning disability.
www.valuingpeople.gov.uk

Young Minds
Provides information on the mental health of children and young people.
www.youngminds.org.uk

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Appendix: Appendix of prescribed medication for mental health problems

10.1 Anti-depressants

These are primarily prescribed for depression. There are several types of anti-depressants and the main two are:

Tricyclic anti-depressants
These include amitriptyline (Tryptizol), clomipramine (Anafranil) and imipramine (Tofranil). They can be sedative in effect and are usually taken at night as a single dose. They can cause side effects such as dry mouth, constipation, blurred vision and difficulty in urination, and can increase the likelihood of seizures for people with epilepsy. They are toxic in overdose and thus not suitable for those with suicidal thoughts.

Selective Serotonin Reuptake Inhibitors (SSRIs)
These are less toxic in overdose. They include fluoxetine (Prozac), paroxetine (Seroxat) and sertraline (Lustral). Side effects tend to be milder and can include nausea and upset stomach, insomnia and agitation. SSRIs are sometimes prescribed to people with anxiety problems such as obsessive-compulsive disorders.

Anti-depressants take several weeks to start working. Once they do start to work people can feel a lot better and may be inclined to stop taking them. They should be taken until the doctor advises that they can be stopped, which is usually a minimum of six months after the depressive episode ends.

10.2 Anxiolytics

Anxiolytics are prescribed for anxiety. They include diazepam (Valium), lorazepam (Ativan) and chlordiazpoxide (Librium). Side effects include drowsiness. They are generally used only for short-term relief whilst other interventions (such as cognitive behaviour therapy) are put in place. This is because people become tolerant to their effects, resulting in a need for an increase in dose, eventually leading to addiction. Anxiolytics have several other uses including calming people who are displaying acutely disturbed behaviour and in the management of status epilepticus (when a person has repeated consecutive seizures).

10.3 Hypnotics

Hypnotics are prescribed for the management of insomnia and include medications such as nitrazepam, zolpidem tartrate (Stilnoct) and zopiclone (Zimovane). The latter two are newer hypnotics and have a shorter effect on the body, thus reducing the 'hangover' symptoms commonly associated with older sleeping pills. Every effort should be made to find out why the individual is having sleep difficulties and appropriate changes made (i.e. avoiding caffeine late at night, taking more exercise and establishing a night-time routine).

10.4 Antipsychotics

These are used to treat schizophrenia and other disorders where psychotic symptoms (i.e. hallucinations and delusions) are present, such as severe depression, manic depression and dementia. There are two groups of antipsychotics; these are:

Typical antipsychotics (typicals)
These include chlorpromazine (Largactil), haloperidol (Serenace) and zuclopenthixol (Clopixol). Side effects include sedation, dry mouth, blurred vision, constipation and difficulty with urination. Some side effects mimic the symptoms of Parkinson's disease such as tremors.

Atypical antipsychotics (atypicals)
These include olanzapine (Zyprexa), quetiapine (Seroqel) and risperidone (Risperdal). These tend to have fewer side effects but can cause weight gain, increased salivation and movement disorders (far less prominent than with typicals). Weight gain can be significant so promotion of healthy eating and exercise is advised. Clozapine (Clozaril) is used when other medications are unsuccessful, often referred to as treatment resistant schizophrenia. It can impair the person's immune system, making them vulnerable to infections, and so is only used when other medicines have failed to help. Due to this regular blood tests are essential.

Some antipsychotics are given in the form of depot injections. These slowly release the medication into the body over a period of time. People may be given regular depots every two to six weeks. They are more likely to be given to people who are likely to forget to take tablets.

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10.5 Mood stabilisers

These are mainly used to treat manic depression (bipolar disorder). They include lithium (Camcolit, Liskonum, Priadel, Li-Liquid and Litarex). Common side effects when starting lithium include nausea, loose bowels, tiredness, thirst and passing excessive amounts of urine. These tend to improve once stabilised. Longer lasting side effects include drinking far more liquid than usual, weight gain, tremor and mild forgetfulness. Lithium can be toxic. It is monitored through regular blood tests. Signs of toxicity include blurred vision, slurred speech, appetite loss, upset stomach and drowsiness or hand tremor. If toxicity is suspected the person's prescribing doctor should be contacted immediately. Pharmacies have information leaflets about lithium.

Some anti-convulsants, which are primarily prescribed for the management of epilepsy, are also used as mood stabilisers. These include sodium valproate (Epilim) and carbamazepine (Tegretol). Possible side effects of carbamazepine are dry mouth, nausea and vomiting. Some people develop rashes but these are not dangerous and disappear once the medication is stopped. Common side effects of sodium valproate include nausea, upset stomach, increased appetite and weight gain.

Some side effects are very significant and medical advice should be sought immediately. These include staggered walk, dizziness, drowsiness, blurred vision, fever, sore throat and unexplained bruising or bleeding.

For further information on medication you may want to refer to the **British National Formulary (BNF)** which is published by the British Medical Association and the Royal Pharmaceutical Society. The current version is BNF 51.

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Supporting Complex Needs: A practical guide for support staff working with people with a learning disability who have mental health problems

Turning Point

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T: 020 7702 2300 F: 020 7702 1456. www.turning-point.co.uk

The Estia Centre

The Estia Centre is a training, research and development resource for those who support adults with learning disabilities and additional mental health needs.

The Estia Centre is based on the Guy's Hospital Campus and is an integral part of local services for people with learning disabilities provided by the South London and Maudsley NHS Trust.

The Estia Centre is also an academic section of the Institute of Psychiatry (Division of Psychological Medicine and Health Service Research Department) of King's College London.

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London SE1 3SS

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