



Royal College
of Nursing

Mental health nursing of adults with learning disabilities

RCN guidance

South London and Maudsley 
NHS Foundation Trust



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Foreword

The Royal College of Nursing (RCN) Learning Disability Nursing Forum works to ensure that the needs of people with learning disabilities are recognised, and met, in mainstream health and social care services. Good mental health is a critical element for everybody in society. The mental health needs of people who also have learning disabilities are especially important.

This guide serves to support and raise awareness of these issues with a wide spectrum of health care providers and carers. The RCN Learning Disability Nursing Forum Committee is delighted that the publication has been produced, and thanks its committee member Steve Hardy, and the Estia Centre, for their hard work in bringing these important issues to people's attention.

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The South London and Maudsley NHS Foundation Trust

This Trust provides one of the most extensive portfolios of mental health services in the UK, including mental health, learning disability and substance misuse services to people from Croydon, Lambeth, Southwark and Lewisham and substance misuse services in Bexley, Greenwich and Bromley. It also provides specialist services to people from across the UK. The Trust works with its partners in health and social care, the voluntary sector and beyond, to promote and improve mental well being in its local communities. The Trust works closely with the Institute of Psychiatry, Kings College London, in developing care that is based on evidence of the best that is possible.

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Introduction

This publication provides guidance for nurses and nursing students in mental health services in delivering high quality health care to people with learning disabilities. It continues the RCN Learning Disability Nursing Forum's work on ensuring that people with learning disabilities have equal access to health care services.

The guidance's main objectives are that those reading it will have:

- ◆ a better understanding of the mental health needs of people with learning disabilities
- ◆ a better understanding of the communication needs of people with learning disabilities
- ◆ the ability to adapt mental health assessments to meet the needs of people with learning disabilities
- ◆ a clearer understanding of Government policy concerning people with learning disabilities
- ◆ the desire to promote joint working between services and professionals and to raise awareness of care pathways
- ◆ a better understanding of specialist services for people with learning disabilities and how these can be accessed.

The publication highlights the vulnerability of people with learning disabilities to mental health problems, how they present, and are assessed and treated. It gives examples of good practice and partnership working.

It is aimed at nurses and nursing students who might work with adults with learning disabilities, but those who work with children may also find it useful. Other health and social care professionals may also find it helpful. The guidance is also suitable for the new professional roles, such as graduate mental health workers as described in *Mental Health: New Ways of Working for Everyone* (DH, 2007).

Many local learning disability services across the UK have already developed comprehensive guides and training packages in this area. This guide does not replace these, but has been developed because of the RCN's unique ability to reach the wider nursing workforce.

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People with learning disabilities

People with learning disabilities are a diverse group. Each of them, like everyone else, has a distinct personality and characteristics, and their own history, values and opinions. They are a group of people who in law have the same rights as any other citizen, though in the past – and frequently today – they continue to be excluded and discriminated against.

Learning disability is one of the most common forms of disability and affects up to 1.5 million (2% of the population) people in the UK. It is a life long condition. People with learning disabilities vary widely in their abilities, affecting the kind of support each person needs.

Defining learning disability

Learning disabilities affect a person's ability to learn, to communicate and carry out everyday tasks. The Department of Health (2001) in England defined learning disability as a combination of:

- ◆ a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence); along with
- ◆ a reduced ability to cope independently (impaired social functioning)
- ◆ an onset of disability which started before adulthood, with a lasting effect on development.

Many services across the UK use more medical and psychologically based criteria to define learning disabilities; such definitions exist in classification systems like ICD-10: Classification of Mental and Behavioural Disorders (WHO, 1992) and Diagnostic Statistical Manual -IV (APA, 1994). These definitions are mainly used when determining whether a person is eligible to use specialist learning disability services, and/or deny access to mainstream services. Recent thinking has seen a shift towards access being based on need and not ability, though its cascade down to the front line of services has been slow.

To determine eligibility, an individual may be assessed on:

- ◆ level of intelligence, using an IQ (intelligence quotient) test. An IQ measured below a score of 70 is generally indicative of learning disabilities. IQ tests are generally administered by clinical psychologists in the health service
- ◆ level of social functioning, covering areas such as communication, personal hygiene or budgeting
- ◆ their history, to see if their disability occurred before the age of 18 years, so whether they meet the last of the Department of Health's components.

Some people who experience other conditions, such as acquired brain injury or chronic schizophrenia, may meet the first two components of clinical definitions of learning disability, but if their condition was developed in adulthood, they would not be considered to have learning disabilities – would not be eligible to use specialist learning disability services.

Degree of learning disability

If you are working with people who have learning disabilities, you may come across references to the degree of learning disability – mild, moderate, severe or profound. These come originally from a medical perspective. Policy makers are now encouraging services to focus on individual needs rather than previous groupings of people with learning disabilities. None the less, these terms are still commonly used in practice, and we set out here broad descriptions you may find useful.

Box 1

Degrees of learning disability

(Adapted from Hardy et al, 2006)

Mild: Over three quarters of people with learning disabilities have mild learning disabilities. The majority of these live independently; many have their own families, are in employment and have no need for extra support from services, except in times of crisis.

Moderate: For people with a moderate learning disability, the level of support needed is higher. Many of them will need some degree of support with everyday tasks and may have difficulty in communicating their needs. They are likely to be living with their parents, with day-to-day support, or in supported living schemes. They are also likely to use a number of support services such as day, outreach and supported living schemes.

Severe/profound: People with severe and profound learning disability may have significantly increased health needs, 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-injury is particularly 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 disabilities can also be described as 'people with high support needs'. This more contemporary language is being used widely, and is included in Government policies.

These are generalised categories, and sometimes people appear to overlap them. For example, someone with autism who has learning disabilities may have significant social difficulties and appear to have moderate learning disabilities, yet may be able to look after their own personal care and everyday needs quite independently.

Terminology

The term 'learning disability' was adopted by the Department of Health in 1992, replacing the term 'mental handicap'. Some people with learning disabilities in the UK prefer to use the term 'learning difficulties' – you need to be aware that this term is commonly used in educational settings, and has a far wider definition. Other terms are used throughout the world and increasingly are used in academia in the UK, such as 'intellectual disabilities'. The outdated term 'mental retardation' is still commonly used in the USA, though services are beginning to use less stigmatising language.

Recognising people with learning disabilities

It is not always apparent that someone has learning disabilities. Some may be easy to identify because they show particular physical characteristics caused by a genetic syndrome such as Down's syndrome, but this is generally not the case. If you can recognise someone's learning disabilities quickly, you can respond more appropriately to their needs, and where necessary seek the advice of specialist learning disability professionals.

It is important to remember that you may encounter a whole range of abilities and needs, from people who live independently and only come into contact with services in times of crises, through those living with their parents or in supported housing where services are generally provided by the private and voluntary sector. A small number of people have more complex issues such as severe and enduring mental health problems, behaviour that is severely challenging, or who are at risk of offending. These people will require more specialist and highly structured services. There are also people with learning disabilities who are in prison.

You can look for a number of indicators in identifying that a person has learning disabilities. It's obvious, but

Box 2

Possible indicators of learning disability in an individual

Activities	Remember	Life experience
<p>Can they:</p> <ul style="list-style-type: none"> • read • write • manage money • look after their personal care • tell the time • cook? <p>Do they have difficulty in communicating with other people?</p>	<p>Can they remember:</p> <ul style="list-style-type: none"> • significant things about themselves (e.g. birthday) • significant things about their environment (e.g. where they live) • when to do things (get up, what time dinner is) • what you have said? 	<p>Have/do they:</p> <ul style="list-style-type: none"> • attended a special school • attend a day centre • live(d) in a hospital or a learning disability service • have people who support them (e.g. care manager, advocate etc) • manage in social situations?

sometimes forgotten, that you can ask them if they have learning disabilities. Box 2 shows areas you can also ask them about, to help identify whether they have learning disabilities.

- ◆ impairment of imagination: people with autism do not develop the same imaginative skills as other people; they tend to think in a very concrete way, for example, thinking in terms of actual objects. They also have difficulty with abstract concepts like emotions.

Autism

Autism is a life long, pervasive developmental disorder. Approximately 25% of people with autism have learning disabilities (Chakrabarti and Fombonne, 2001). The majority of people with autism who do not have accompanying learning disabilities are described as having either ‘high functioning autism’ or Asperger’s syndrome.

Autism is referred to as a ‘spectrum disorder’, because it varies considerably in how it affects each person. However, here are three core features of autism and these affect all aspects of the individual’s life:

- ◆ impairment of communication: this affects both verbal and non-verbal communication. Some people may present with echolalia, repeating what they have heard. Difficulty understanding certain types of words, such as abstract concepts and negatives, is common
- ◆ impairment of social interaction: this can range from someone who seeks out social interaction, but lacks the social skills to develop and maintain relationships, to someone who is withdrawn and apparently indifferent or actively avoids other people

Challenging behaviour

‘Challenging behaviour’ is a term often used by services for people with learning disabilities. Its definition is slightly different to that used in mental health services.

The most commonly used definition is:

‘Culturally abnormal behaviours of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to and use of ordinary community facilities.’ (Emerson, 1997).

Challenging behaviour covers a wide range of behaviour, such as aggression, self-harm and anti-social behaviour. It is relatively common – 6% of people with learning disabilities present with severe behavioural challenges (Emerson, 1997).

Challenging behaviour is more commonly associated with people with higher support needs.

The causes of challenging behaviour are numerous, including communication needs, poor environment,

abuse, physical discomfort, or a mental health problem. In rarer instances, it can be a behavioural phenotype in particular genetic syndromes, such as severe self-harm in Lesch-Nyhan syndrome.

Person-centred active support (PCAS) is the cornerstone of meaningful and long-lasting positive behavioural change for people who show challenging behaviour. The PCAS model focuses on helping people engage in meaningful activities and relationships throughout the day. Once this is in place, professionals can make a comprehensive functional assessment of behaviour, and implement intervention. Such intervention usually includes altering the environment in which the behaviour occurs; positive programming (which would mean further long-term work and new skills teaching); direct treatments to bring severe challenging behaviour under rapid control; and reactive strategies to provide consistent and constructive support for when challenging behaviour occurs.

Offending behaviour

Offenders against the law who have learning disabilities, mental health problems and/or behavioural problems that require interventions from a specialist mental health team, are subject to the same legislation and pathway through the criminal justice system as other mentally disordered offenders. This pathway is designed with safeguards to protect the rights of the individual and to divert where appropriate, this is helped by initiatives such as the appropriate adult scheme (appropriate adults are required by law when vulnerable adults are identified at the police station). Appropriate adults represent the person in order to guarantee their welfare. They should ensure that they are being treated appropriately by encouraging effective communication and making sure that the process is fair. Other safeguards can be provided at service level, such as local Police Liaison Schemes that operate as a two way process, with the eventual aim being that the person, whether a victim or perpetrator, is treated in a way that makes the whole process fair, accessible and controlled.

The assessment and treatment of this small group of people requires specialist knowledge – misinterpreting the way an individual presents could ultimately affect their liberty, or could compromise public safety. Some areas where you might observe differences in the way such people present. Examples of this include:

- ◆ acquiescence, which makes the individual less likely to protest and answer in the affirmative. This may mean they cover up limitations, seek approval or praise
- ◆ suggestibility, this means the individual may be more responsive to suggestions and be positive towards them, which could have serious consequences if being formally questioned
- ◆ diagnostic overshadowing. This is where the assumption is made that the way the person presents is due to their learning disability and therefore part of their normal presentation
- ◆ psychosocial masking. This limits the expression of psychiatric symptoms often due to limited life experiences. Symptoms may appear to be childlike fantasies or have a less complex presentation which may lead to severe symptoms being missed.

This is a diverse group, and their offending patterns are mixed. Some people with learning disabilities, as you would expect, are treated within mainstream forensic services such as medium secure units and community placements for offenders. Usually this group will have more in common with their peers in terms of index offence (this is the offence that the person has been convicted of and which led to the current spell in detention) and overall clinical presentation. However, others may be placed into the care of specialist services for a number of reasons:

- ◆ vulnerability to their peers
- ◆ the need for specialist expertise
- ◆ access to structure and treatment programmes not available within mainstream services
- ◆ unsuccessful treatment episodes within mainstream services.

The Care Services Improvement Partnership has recently produced guidance for professionals in the criminal justice system on working with offenders with learning disabilities (Betts and Zammit, 2007). Copies can be downloaded by visiting www.kc.csip.org.uk.

3

Policy and law

Policies about people with learning disabilities around the UK

Each of the four UK countries has its own Government policy on how the needs of people with learning disabilities should be met. Though different in structure and implementation, there are common themes that underpin all four:

- ◆ people with learning disabilities are equal citizens, who have the same rights as any other person
- ◆ empowering people to make their own choices and take control of their lives
- ◆ the right to be offered the same opportunities as other citizens
- ◆ the right to be independent
- ◆ social inclusion becomes a reality for people with learning disabilities.

The UK policies on people with learning disabilities are:

- ◆ England:

Department of Health (2001) *Valuing people: a new strategy for learning disability for the 21st century*, London: DH.

- ◆ Northern Ireland:

Department of Health and Social Security (2005) *Equal Lives: Review of policy and services for people with a learning disability in Northern Ireland*, Belfast: DHSSPS.

- ◆ Scotland:

Scottish Executive (2000) *The Same As You: A review of services for people with learning disability*, Edinburgh: Scottish Executive.

- ◆ Wales:

Learning Disability Advisory Group (2001) *Fulfilling the Promises: Report of the Learning Disability Advisory Group*. Cardiff, National Assembly for Wales.

Each policy addresses mental health needs in various

ways, but focuses on similar issues, including:

- ◆ promoting collaborative working between mainstream mental health services (primary and secondary care) and specialist learning disability services
- ◆ people with learning disabilities to access mainstream mental health services wherever possible
- ◆ small, specialist inpatient services for those whose needs can not be met by mainstream services
- ◆ a changing role for specialist learning disability services, providing support and facilitation for mainstream services
- ◆ mainstream mental health care staff to receive adequate training on the needs of people with learning disabilities
- ◆ in England and Wales, applying the care programme approach for people with learning disabilities with mental health problems
- ◆ mental health promotion materials are made accessible to people with learning disabilities.

These policies have been specifically developed for people with learning disabilities, but it is vital to remember that all Government policies and laws apply to people with learning disabilities as to everyone else.

An example

The Green Light Toolkit (GLTK) (FPLD et al, 2004) is one example of how these policies are being implemented. It is used throughout England and in some parts of Wales. The GLTK is an audit tool used to measure how the National Service Framework for Mental Health (DH, 1999) is being implemented for people with learning disabilities.

The toolkit provides standards that local, mainstream mental health and specialist learning disability services, in collaboration with key stakeholders, can measure their services against. It offers a 'traffic light' scoring system and provides guidance on how services can be improved. It covers area such as local partnerships, planning, accessing services, care planning, workforce

planning and diversity. Responsibility for the GLTK lies with the National Service Framework local implementation teams (LIT) and learning disability partnership boards. These partnership boards are groups of people with learning disabilities, carers and representatives from local statutory and voluntary organisations who meet regularly to help develop local policy and services. After a GLTK assessment, each local area should develop an improvement plan.

Mental health law

It is a prerequisite for mental health nurses to have a good working knowledge of mental health legislation in their respective countries. Too often, the Mental Health Acts are disregarded for people with learning disabilities who also have mental health problems, denying them safeguards and the protection of the law. Where appropriate, the relevant legislation should be applied to individuals and the same categories of detention used as for other individuals (for example, in England if a person has a mental illness, they should be detained under 'Mental Illness' opposed to 'Mental Impairment').

The Acts for the UK countries are:

The Mental Health Act (1983) and the Mental Health Bill (England and Wales)

www.dh.gov.uk

The Mental Health (Amendment) (Northern Ireland) Order 2004

www.opsi.gov.uk

The Mental Health (Care and Treatment) Act Scotland (2003)

www.scotland.gov.uk

Consent

In all four UK countries, there is either law or guidance providing a framework for acting and making decisions on behalf of those who lack capacity to make decisions for themselves. Law and guidance on consent serve the population as a whole, which includes people with learning disabilities.

The UK has two laws on capacity to consent, the *Mental*

Capacity Act (DCA, 2005) for England and Wales, and the *Adults with Incapacity Act* (Scottish Executive, 2000) in Scotland.

Northern Ireland has no statute on consent, but legislation is being developed as part of the overall Review of Mental Health and Learning Disabilities in Northern Ireland (www.rmhdni.gov.uk). Current practice should be based on the current guidance: *Reference Guide to Consent to Examination, Treatment and Care* (DHSSPS, 2003) which is based on case law.

Although the Acts and case law differ in terminology and procedures, they are based on similar principles and have similar expectations of health and social care professionals.

The underlying principles in both Acts and the Northern Ireland Guide to Consent are that every adult has the right to make his or her own decisions, and that it must be assumed that a person has the capacity to make a decision unless proved otherwise. This is a change from the earlier 'status' approach to capacity – that is, what or who you are determines your ability to make a decision. This approach led to people with learning disabilities being denied the opportunity to make even basic decisions about their lives.

Assessment of capacity

The assessment of capacity should be specific to making a particular decision, and should be made at the time that decision needs to be made. Capacity can change over time; because a person was previously unable to make a decision, does not mean you should assume that they still cannot. Some people may be able to make some decisions, but have difficulty with others so, again, it is important that you treat each decision independently.

The assessment of capacity should be based on:

- ◆ whether the person understands and retains the information about the decision
- ◆ whether they are able to weigh and balance the information to make a choice
- ◆ whether they are able to communicate that choice through whatever means of communication they use (verbal, sign language, written).

People with learning disabilities might have difficulty

understanding information, and should be supported as much as possible in the decision-making process. This involves providing them with all the relevant information in a format they will understand (such as pictures, symbols or audio). Speech and language therapists can advise you on how to give the information to individuals. Clinical psychologists can assess cognitive functioning (although this is not indicative of a person's capacity), test for suggestibility, and assess the individual's knowledge about the decision to be made.

Acting on someone's behalf

If a person is assessed as lacking capacity, decisions can be made on their behalf, as long as it is in their best interests. Acting in someone's best interests means considering their past and present wishes, beliefs and values. Whenever possible, the care team should seek the views of their family, friends, advocates and anyone they have appointed. The team must weigh up possible advantages and disadvantages of making a particular decision, taking into account the person's medical, emotional and social welfare. The decision the team takes should be the least restrictive option in terms of the person's rights, freedom and quality of life. If the decision is medical, then the current body of medical evidence and opinion should support the chosen course of action.

Over recent years in England, there has been much legal discussion about the rights of those who lack the capacity to consent to, or to refuse, admission to hospital for treatment. Where it has been deemed inappropriate for the person to be sectioned under the Mental Health Act (1983), individuals are admitted to hospital informally, but are thus effectively deprived of their liberty in order to give them care or treatment. Legislation is currently being developed to close this legal gap, and will be introduced into the Mental Capacity Act (2005). Until such time, interim guidance, entitled 'The Bournemouth Safeguards', has been drafted (available at www.dh.gov.uk).

The Department of Health in England (DH, 2001) and Department of Health, Social Services and Public Safety in Northern Ireland (DHSSPS, 2003) have both produced leaflets about consent for treatment for people with learning disabilities (available at www.dh.gov.uk and www.dhsspsni.gov.uk).

4

Services

Specialist learning disability services

Most people with learning disabilities live in the community and have the right to equal access to mainstream health services. However, specialist services are sometimes needed to provide additional support.

- ◆ social workers/care managers
- ◆ speech and language therapists.

Some teams also include hearing and visual therapists, challenging behaviour workers, and community psychiatric nurses. To find out if your local area has a CLDT, contact your local primary care trust or social services department.

Community teams

Most health districts across the UK have a team providing specialist health and social care to people with learning disabilities who live in the community. These are commonly called community teams for adults with learning disabilities (CLDT), but names differ in some areas.

Teams are generally made up of staff from a mixture of organisations, including social services, primary care trusts and, sometimes, mental health trusts.

National policies advocate that people with learning disabilities should be able to access mainstream health services, and CLDTs promote this by providing specialist advice and support to their mainstream colleagues. Some CLDTs operate a life-span approach, but the majority work with people only from adulthood onwards. Intervention by CLDTs usually occurs when someone has additional complex needs, such as problems with communication, challenging behaviour or mental health problems.

Many services operate an open referral system, accepting referrals from the person themselves, relatives or carers, or health and social care professionals. People with high support and/or complex needs will probably already be known to the CLDT.

CLDTs employ a wide range of specialists, including:

- ◆ community learning disability nurses
- ◆ occupational therapists
- ◆ physiotherapists
- ◆ psychiatrists
- ◆ psychologists

Specialist in-patient services

Some health districts in the UK provide specialist in-patient beds for people with learning disabilities who have additional needs, such as mental health problems, severe challenging behaviour and, occasionally, for the acute management of epilepsy.

These services are for people who are unable to use mainstream services because they are particularly vulnerable or have complex needs, and require specialist assessment and treatment.

Working in collaboration

A common goal throughout UK learning disability policy is that individuals should use mainstream mental health services wherever possible. This is a relatively new concept for many services and has not been met without difficulty.

Learning disability and mainstream mental health services have a history of working separately, sometimes with disagreements over boundaries and eligibility. Services are now beginning to develop mutual understanding of the mental health needs of people with learning disabilities. They are beginning to work in partnership, breaking down service boundaries and working towards a common goal of providing person-centred, high quality mental health services to this vulnerable group. Box 3 highlights some examples of how progress is being made.

Box 3

Examples of working in collaboration

Implementing policy

The learning disability and adult mental health services of **Leicestershire Partnership NHS Trust** jointly audited their mental health services for people with learning disabilities, using the Green Light Toolkit. They worked in partnership with people who use services, carers, local authorities and the private and voluntary sector. From the audit, they developed a strategy that addressed service interfaces, training, advocacy, carer involvement and accessibility of information.

Joint protocol

Hampshire Partnership NHS Trust developed a clinical interface protocol between learning disability and adult mental health services. The protocol describes the operational arrangements between the two services, to ensure that people with learning disabilities are seen efficiently and receive support from both or either service as appropriate. The protocol was jointly developed between the two services and also involved people using local services.

Training

Merseycare NHS Trust developed a training programme on the mental health needs of people with learning disabilities. The programme brought together nursing staff from both learning disability and adult mental health services. Programme content included rights, values, recognising people with learning disabilities, assessment and different treatment and therapeutic approaches. The training programme also raised awareness of the Joint Working Protocol between the Learning Disabilities Directorate and Adult Mental Health Services. The programme was positively evaluated.

Specialist mental health in learning disabilities service

South London and Maudsley NHS Foundation Trust provides a specialist secondary and tertiary mental health service. The service is an integrated part of local mental health services and works closely with local community teams for adults with learning disabilities and social services. The team consists of psychiatrists and community psychiatric nurses and has access to all the facilities of mainstream mental health services, including admission where appropriate. The service has a small specialist admission ward for those where mainstream admission is not appropriate.

Joint virtual team

Camden and Islington Mental Health and Social Care Trust developed a 'virtual' mental health team for people with learning disabilities. The team provides specialist health care, care management, early intervention and community support. The team has representation from adult mental health inpatient services, learning disability health and social services. There are also allocated beds within a mainstream mental health ward, with additional staffing provided and a training programme on the needs of people with learning disabilities.

5

Vulnerability to mental health problems

There was little acknowledgement in the past that people with learning disabilities can develop the same mental health problems as the wider population. Today, we recognise that people with learning disabilities demonstrate the complete spectrum of mental health problems, with higher prevalence than found in those without learning disabilities (Cooper et al, 2007).

Most recent research into the epidemiology of mental health problems in people with learning disabilities puts prevalence rates between 20.1% -22.41% (excludes challenging behaviour) in adults with learning disabilities (Taylor et al, 2004, Cooper et al, 2007) compared to 16% in the wider population (DH, 2003). Research suggests a rate of 36% (including conduct disorder) in children with learning disabilities (Emerson and Hatton, 2007) compared to 10% in children from the wider population (DH, 2005).

Factors contributing to mental health problems

The increased prevalence of mental health problems in those with learning disabilities has been attributed to increased biological, psychological and social factors that may predispose, precipitate and perpetuate mental health problems (Deb et al, 2001). These vulnerability factors can affect anyone, but by virtue of their disability, people with learning disabilities are more likely to encounter them. As in the wider population, it is likely that an interaction of factors leads to the development of mental health problems.

Biological factors

◆ Brain damage

Although most people with mild learning disabilities do not have brain damage, for some, brain damage may have caused their learning disability. This damage can cause structural and physiological changes to the way the brain functions, increasing vulnerability.

◆ Sensory impairments

People with learning disabilities have higher levels of hearing and sight difficulties. This becomes even more

apparent in people with more severe learning disabilities or in some genetic syndromes. Sensory impairments are often undiagnosed. Sensory problems can cause a barrier to social integration and lead to disablement.

◆ Physical health problems transitory illness / infections

Physical disabilities and illness are increased in people with learning disabilities. The effects of physical impairments are exaggerated by a lack of understanding in wider society, such as through poor accessibility to buildings and facilities.

◆ Genetic conditions

Some genetic syndromes are risk factors to particular mental health problems. For example, Down's syndrome greatly increases the likelihood of developing Alzheimer's disease.

◆ Medication

People with learning disabilities are likely to receive medication for a variety of physical, neurological and psychiatric reasons. The side effects of medication, particularly when the person is in receipt of two or more psychotropic medication, need to be considered as they can contribute to mental health problems.

◆ Epilepsy

Approximately a third of people with learning disabilities have epilepsy. Epilepsy is associated with the symptoms of mental health. Having epilepsy can provoke anxiety in an individual, meaning for example that they avoid going out on their own and become isolated.

Psychological factors

◆ Self-insight and self-worth

Our society values certain accomplishments, such as achieving high social status, independence, employment, relationships and a family. People with learning disabilities may have difficulty achieving these things, which may affect their self esteem.

◆ Self-image

People with learning disabilities may feel they are

different to other people. Some may have physical disabilities that set them apart from others, or may feel that they are inferior because they are more reliant on the support of others. A poor self-image can be a catalyst for a mental health problem.

◆ **Poor coping mechanisms**

Although many people with learning disabilities cope under very difficult conditions, some do not have the same capacity to handle their circumstances. Cognitive deficits might make it more difficult for people to plan ahead or consider the consequences of their actions. A lowered tolerance of frustration can lead to anger management problems – and thus greater discrimination by other people.

◆ **Bereavement and loss**

People with learning disabilities will encounter bereavements, but may not receive the support they need to cope with what has happened. They might be excluded from any customs associated with the bereavement, be suffering feelings others don't recognise, or given no opportunities to discuss these feelings. Sometimes, they may not even be told about what's happened. They may be similarly affected by their experience of other losses – for example, siblings leaving the family home, staff leaving supported housing, or other service-users moving on.

◆ **Difficulty expressing emotions**

People with learning disabilities may have trouble in articulating their inner thoughts and feelings, perhaps because speech and language difficulties prevent them putting subtle and abstract emotions into words.

◆ **History and expectation of failing**

People with learning disabilities often encounter discrimination by not being given opportunities, so they develop low expectations of themselves. Frequent exposure to failure may lead some people with learning disabilities to develop learned helplessness, which can in turn lead to a lack of motivation and poor goal setting.

◆ **Dependence on others**

Social conditioning can lead people with learning disabilities to rely on others for support, which can create over-dependency, a lack of self-determination and poor problem solving skills.

Social causes

◆ **Living in inappropriate environments**

Although the majority of people with learning disabilities live with their families, some older people may have lived segregated in institutions. Others may have lived in residential settings where they had little control and choice in their lives. Such environments may provide little to do, or too much stimulation from noise and the challenging behaviour of others.

◆ **Exposure to adverse life events**

People with learning disabilities are more likely to be exposed to abuse or may have had episodes of bullying and harassment. They are also vulnerable to exploitation and may not be aware of their rights.

◆ **Expectations of others**

Unfortunately, the expectations of those around people with learning disabilities can be low. They can deny opportunities to people with learning disabilities because they feel that they will fail or are too vulnerable. This can mean that people with learning disabilities are not given the opportunity to live as independently as they could do, and can become over-dependent.

◆ **Family**

The majority of carer families provide good support, often under difficult circumstances and with inadequate assistance. The strain of caring for a family member with a learning disability may, however, cause stress or lead to financial hardship. It can affect the family members' relationships with the individual.

Some family members can also be over protective of those with learning disabilities, reducing opportunities for the individual or leading to over-dependence.

◆ **Reduced social networks**

People with learning disabilities often have smaller social networks and as a result are deprived of the support of a wide network. They may lack the skills needed to develop relationships or may only have superficial friendships with the staff that support them. Others may develop abusive relationships or mix with inappropriate peer groups in an attempt to fit in. The lack of positive interactions can lead people with learning disabilities to feel they must try and please others for social reinforcement, leading to unbalanced relationships.

◆ Lower socio-economic groups

People with learning disabilities are more likely to be born into and live in lower socio-economic classes. This can make them even more disadvantaged.

◆ Transitions

Transitions between services are often poorly managed for people with learning disabilities. Problems often arise when adolescents make the transition into adulthood, with poor communication between child and adult services and bad planning adding to the problem. The individual may feel they have little control or influence over what happens to them.

◆ Discrimination

Society has long discriminated against and rejected people with learning disabilities, who are often stigmatised. This can have an impact on their self-esteem and self-image.

◆ Legal disadvantage

People with learning disabilities may not be aware of their rights as citizens. They often have to rely on the support of others to be advocates for their needs.

6

Assessment of mental health problems

There are a number of ways in which both the experiences and abilities of people with learning disabilities may differ from those of other people accessing mental health services. These will affect how an individual may present in an assessment, how you support them through the assessment process and how you communicate with them. Every person is different, however, and may demonstrate a variety of the characteristics given here, or none of them.

Although the assessment process may be similar, there will be areas that you may find of greater significance in explaining an individual's presentation and needs. You may need to explore further to clarify some aspects. Extra attention to detail will help you make the correct formulation, and enable you to engage with and understand the individual, and develop an appropriate intervention plan. To achieve this, you will need to work in partnership not only with the individual, but with family carers, support staff and professionals from other services.

During the assessment

In any mental health assessment, it is essential that you develop a therapeutic relationship, working in partnership with the individual and their carers.

People with learning disabilities may become anxious when they meet mental health professionals, and there are strategies that you can use to make them feel more at ease and get the best results from the assessment.

Communication

Communication is central to making a sound assessment. It is estimated that at least 50% of people with learning disabilities have significant communication difficulties (Mansell, 1992). It is quite common for a person's receptive and expressive communication to be at different levels, i.e. they may understand more or less than they appear to from their verbal skills.

You need to address the particular communication needs of each individual, as each will vary in their

abilities. Before you meet them, find out about their needs by checking their file or contacting their GP for a copy of any speech and language therapy report (which may contain communication strategies).

Box 4 sets out some of the common communication needs that nurses may come across and offers ideas on how these can be met. Resources such as websites and publications to enhance communication with people with learning disabilities are listed in Section 9.

Other factors during the assessment

- ◆ Avoid unpredictability, it breeds anxiety. Make everything as predictable as possible, explaining who you are, where they are, the purpose of your meeting and how long it will last. Start by sending them information before the assessment, explaining all these points in a way that they understand and including a photograph of the professional they will be seeing. Continue to explain things throughout each stage of the communication. It may also be beneficial for the individual to visit care settings before their appointment/admission.
- ◆ Consider a person's special needs, such as visual and hearing impairments, physical accessibility and cultural needs.
- ◆ Choose the best venue – preferably an environment they know, and wherever possible a place of their own choice. Consider seeing them more than once to cover a number of different environments, as their behaviour and anxiety levels are likely to change depending on where they are. This could include the clinic, their home, where they spend their daytimes, etc.
- ◆ Plan the assessment in advance. Make sure it has a clear beginning, middle and end. Plan your questions, write them down and check them against the communication advice in Box 2. As you may be asking questions about things the individual may not have experienced, gather a list of alternative, 'easier' words – for example 'nervous' instead of

Box 4

Meeting communication needs

The individual's communication need	Ways to meet the need
Uses sign language such as Makaton or BSL, or communication aids	May need a carer to support them when you see them
Has difficulty with technical or medical jargon	Use simple, everyday language
Takes longer than others to think about the questions you have asked and to formulate a response	Allow sufficient time for the person to answer your question
Has thoughts and opinions which differ from those supporting them	Always speak to the person with learning disabilities first
Finds quick speech and long sentences confusing	Speak clearly and not too fast. Use short, plain sentences, no more than 10 words per sentence if possible
Has difficulty in digesting new information	Use only one or two new information-carrying words per sentence. Try visual aids such as photos, pictures or symbols to support information-carrying words
Finds too many information-carrying words confusing	Once information has already been introduced, maximise it to four information-carrying words per sentence (e.g. psychiatrist, assessment, Monday, 10 o'clock)
Finds abstract terms difficult to understand	Use simple terms wherever possible. When using abstract terms such as sadness, depressed, use visual aids to support the words. Avoid metaphors and idiom
Finds negative words (eg, no, don't, can't) difficult to understand (often a problem with autism). For example, "You cannot leave the ward"	Use positive language wherever possible. For example, "I will ask the doctor when you can leave the ward"
Finds pronouns hard to understand. For example, "Your tribunal (noun) is Monday. It (pronoun) will be held at 3 o'clock"	Use nouns all the time. For example "Your tribunal is on Monday. The tribunal will be held at 3 o'clock"
Has difficulty in recalling when something happened	Use anchor events in their life, such as holidays, Christmas, birthdays, seasons, the activities they do
Is easily suggestible, especially if they consider the other person to be in a position of authority, such as a doctor or nurse	Try to use open-ended questions. You could use closed questions later on in the conversation to clarify understanding
Agrees with whatever you have said	Try asking the same question but in a different way later on. Bear in mind that some people may think they gave you the wrong answer earlier
Appears to understand or pretends that they understand what you have said.	Ask them to explain to you what they have understood.

'anxious', 'sad' instead of 'depressed'. If the individual does not understand a question, they may react atypically, becoming confused, angry, agitated, mute or behave inappropriately.

- ◆ Allow enough time. The assessment process for people with learning disabilities may be more in-

depth, and might require a longer meeting or having several shorter meetings. Adjust according to the person's attention span.

- ◆ Put them at ease – you could start by asking some questions you know they will be able to answer.

- ◆ Invite someone to support them. It may be helpful for the individual to be accompanied by someone else (with the individual's consent). The second person offers support and reassurance, and can help provide historical information or clarify particular issues such as potential signs of a mental health problem. However, remember to direct your questions at the person with learning disabilities – it is they who are being assessed.
- ◆ Check understanding. Throughout the interview, you will need to establish how much of the information the individual has understood and retained. You can do this by summarising and recapping what you've said. This will help you identify if your questions are pitched at the right level for this person. Reframing the same question will show if the individual's answers are consistent.
- ◆ Be aware of how you come across. How the interviewer presents themselves – in speech, demeanour, dress, etc – can set up a strong initial response and influence the interaction. There is no right or wrong way of doing things, but just be aware that what you say or how you look may set the tone.

History taking

Taking someone's history is an integral part of the assessment and is key to diagnosis. Without a good history, it will be difficult for the clinician to make an accurate diagnosis, as they need to know the context in which a problem has developed and how an individual's experiences have contributed to their position today.

History taking also helps with intervention planning. It can indicate triggers, risk factors and early warning signs, reducing the likelihood of relapse and increasing protective factors. It can show the possible course of the mental health problem and allow us to see how the person has responded to previous interventions. Here are some salient points for taking a good history.

The presenting issue

Professionals working in mainstream mental health services often ask, 'how can you tell the difference between the person's learning disabilities and the mental health problem?' The answer lies with good history taking and observation.

Someone's learning disabilities will have been present since childhood, and in many cases since birth. They will have developed unique personalities with individual behavioural traits and abilities. It is vitally important to build a picture of what constitutes 'normal' functioning for this person, including all their idiosyncratic behaviours. Some of these may appear aberrant against the wider population, but may be perfectly normal in the context of the individual's learning disabilities and life experiences. Building a clear picture of this person's normality also avoids 'diagnostic overshadowing'. This is where professionals disregard significant psychopathology as being part of the person's learning disabilities – see Box 5 for examples.

Establish exactly what the individual and those around them think the problem is, the reasons behind the referral and why the person has been referred now. You should record when, and for how long, changes have been occurring and the impact on the person's everyday life should be recorded.

Consulting others

With mental health problems, others often notice a difference in an individual. When you are compiling someone's history, talk to others close to them who may be able to report on things that may have not appeared significant to the individual. Third parties may also be able to fill gaps if the individual's memory is poor or they can't put events into a context you can understand.

Though the involvement of carers and support staff is advantageous, it remains very important that you involve the person with learning disabilities in the assessment process. Not only is it their right to be consulted, but their opinions about what has been happening to them may be very different from those of other people.

Life events

Carers may view changes in someone's behaviour as due to a mental health problem (that is, something within the person), without considering that the behaviour may stem from the person's environment or relationships.

Explore recent life events and possible stressors, including in particular:

- ◆ physical illness

Box 5**Possible normal behaviour in the context of learning disabilities**

Possible normal behaviour in someone with learning disabilities	Abnormal in the context of mental health problems
Echoing – repeating what they have heard. Very common in people with autism	Echolalia – may be helpful in diagnosing major psychoses such as schizophrenia. Can also be present in autistic spectrum disorders
Overactive – may be very active but not meet the threshold for any psychiatric diagnosis. The overactivity is part of the person's personality and has a consistent pattern	Hypomanic – behaves differently from how they would normally. As well as being overactive, thought processes may also be abnormal (e.g. feeling grandiose and have racing thoughts). May become disinhibited or promiscuous
Very active imagination or fantasy world, such as having imaginary friends.	Auditory hallucinations and delusions, indicative of a psychiatric illness.

- ◆ traumatic experiences (e.g. abuse, accident)
- ◆ bereavements (family, friends, staff, pets)
- ◆ staff changes (in supported housing, day services, outreach teams, social worker)
- ◆ changes in routine
- ◆ changes in family structure
- ◆ changes in relationships
- ◆ transitions (moving home, leaving college, changing day service).

Other aspects

Pay particular attention to the following when you are taking a history of someone with learning disabilities:

- ◆ family – genetic issues, epilepsy, pervasive developmental disorders (e.g. autism), medical and psychiatric disorders, relationships
- ◆ personal – milestones of development, education (mainstream or special schooling), psychosexual, transitions, life events, abuse, relationships, employment, daytime activities, forensic issues, challenging behaviour, professional involvement (mainstream/specialist)
- ◆ medical: cause of learning disability, past illnesses, ability to report illness, current and past medication, blood tests and other medical investigations, attitude to health needs
- ◆ psychiatric: ADHD, past episodes of mental health problems (onset, presentation, course, medical treatment, response, side effects, dose, efficacy,

compliance, preparation, consent, psychological treatment, outcome etc).

Mental state examination

The Mental State Examination (MSE) is a fundamental part of any mental health assessment and a key skill that both mental health and learning disability nurses should possess.

The structure of the MSE should be similar to that used with the wider population, but you should take account of the person's communication needs and how you ask questions (see page 17 for advice). Take a history before the MSE, so that you can compare a picture of the individual's normal functioning and long-standing idiosyncratic behaviour against the presenting issues.

When you undertake an MSE of someone with learning disabilities, you should be particularly aware of the following:

◆ Appearance

This can give us clues or provide red herrings; a smart, well-groomed person at outpatients: is this a reflection of ability and self care, or have they had help from a caregiver? There may be evidence from someone's appearance that they have a genetic syndrome, they could show marks denoting self injury, and so on.

◆ Behaviour

Some people with learning disabilities, especially those who have been in care for sometime, may be used to being supported by a large and changing group of people. They may be quite trusting or over-familiar with people, even strangers or those they perceive to be in a

position of authority. You need to consider whether this behaviour is normal for them, or a sign of hypomania. You may encounter hostility, which could be due to feelings of paranoia, or simply that the person does not understand or has not been informed about why they are there. Psychomotor abnormalities are often associated with mental health problems, but are also common among people with learning disabilities. Stereotyped or ritualistic movements are common among people with higher support needs and/or autistic spectrum disorders, but can also be a sign of a mental health problem. Consider the possible 'movement' side effects of medication.

◆ **Speech**

Speech may reflect ability, although it can make us over-estimate a person's ability. A confident 'yes' or street talk may often mask a lack of understanding and may be mechanisms an individual uses to help them fit in. Abnormal speech may give clues to developmental delays or coexisting physical impairments – but it can also help diagnose mental illness. For example, look out for a monotone voice, echolalia, neologisms (making up new words) and pronominal reversal (replacing 'I' for 'you', so 'you want a bath' means 'I want a bath'). All of these may be part of a schizophrenia spectrum disorder or of an autistic spectrum disorder.

◆ **Mood**

Ask the individual about their subjective experience, beginning with open-ended questions. Pictures and photographs may help them identify the different emotions they are experiencing. Some individuals may have problems in reporting their emotional state for a number of reasons (for example, difficulty in understanding emotions). In these instances, your observations will play a greater role in diagnosing mood disorders. Reports from the person's carers may also be helpful. Compare the individual's current emotional state to what your history taking showed as their normal range of expression: elation, euphoria, withdrawal or irritability might have clinical significance.

◆ **Thought content**

Put the individual's current presentation into context of their normal range of functioning and life experiences. It is changes in thought content that might indicate a mental health problem.

- ◆ Consider the person's developmental level: for example, they may not be able to recognise the

boundaries between the real and imaginary world, so could exhibit role playing or talking out loud to imaginary friends or foes without suffering from a mental illness.

- ◆ You could misinterpret someone's thought content as delusional if they can't offer rational explanations for some of the things they say, or are unable to support their ideas. For example, a man with high support needs may tell you that he can drive and be quite insistent about this. Talking to a carer, you find out that while he was living in a long stay hospital, the porters let the man drive the milk float around the grounds. An individual may say something that you would consider normal within the wider population, but given this individual's life experience and abilities, could in fact be grandiose.
- ◆ People may develop persecutory ideas, but you need to check these carefully, as they could be a genuine sign of bullying or past negative experiences.
- ◆ Suicide and homicidal acts are less common in people with learning disabilities, but they do occur. An individual may also experience suicidal or violent thoughts, but lack the ability to act on them.

◆ **Perception**

Hallucinations can often be difficult to pick up in people with learning disabilities. Individuals may have great difficulty in understanding direct questions about auditory hallucinations (e.g. 'Do you hear voices when no one is around?'); they may also misinterpret their own thoughts as a voice. Some people may experience 'authorisation' of their own thoughts, where they hear a relative or friend's voice telling them what to do, especially to help with difficult situations. You need to assess carefully olfactory or visual hallucinations, as they may be an aura of a pending seizure.

◆ **Cognition and insight**

These will vary along with the person's level of ability – their concentration, orientation and memory may all be affected. This part of the assessment may have an important bearing on diagnoses such as dementia (which may have an earlier onset in people with Down's syndrome). You will need to tailor the type of questions you ask, and put them in context of the person's life. For example, when you are investigating orientation, rather than asking who is the prime minister, ask them who is

the manager at their supported house; instead of asking them the date, you might ask what day of the week they do a particular activity.

There are particular behavioural characteristics that may raise suspicion that someone does have a mental health problem:

- ◆ behavioural disturbances that occur across all settings
- ◆ behavioural disturbances that do not respond to well-designed, consistent behavioural intervention and habilitative programming
- ◆ behavioural disturbances that are associated with concurrent changes in sleep, appetite, sexual activity and/or daily functioning
- ◆ evidence of hyper-arousal with increased autonomic activity (e.g., tremors, fast pulse, sweating) accompanying the behaviours.

Any of these, along with other evidence, could assist you in making an appropriate treatment decision (Pomeroy, 2006).

Physical examination and investigations

Physical health examinations are good practice in mental health care because people with learning disabilities often have undiagnosed physical health problems which may predispose, precipitate or maintain a mental health problem. Examples include thyroid disease, recurrent urinary tract infections or pain. The side effects of some medications can also cause mental health problems, such as some beta-blockers causing depression and some anti-convulsants causing hypomania.

Sometimes, by treating the physical problem one also treats the mental health problem. In other instances you will need to treat the mental health problem concurrently. Along with routine health investigations, MRI, EEG, chromosome studies, or genetic screening may be indicated. These may explain why a certain behaviour might be more likely in this individual (for example, frontal lobe damage is associated with violence, disengagement and disinhibition) or identify a condition with a behavioural phenotype, such as behaviours associated with particular genetic conditions, like overeating in Prader-Willi syndrome.

Aids to assessment

Detecting mental health problems can be made easier if you use good observational recording, which should be inherent in everyday mental health practice. Its effectiveness is often underestimated. Observational records are even more valuable when a person with learning disabilities does not report changes in their mental state, because they underestimate their significance or can't express their thoughts. People who live in supported housing, and sometimes those living in the family who have input from the CLDT, are often undergoing a number of observations. These can be helpful in your assessment, so ask carers or support staff if they have been collecting any of the following:

◆ Sleep charts

Recording the sleep/wake cycle gives us clues, including early or late wakening (signs of depression), lack of sleep (sign of hypomania) or any cyclic patterns common in bipolar disorder

◆ Weight charts

Weight gain and weight loss gives evidence of how someone is looking after themselves; lack of or increased appetite can be a sign of a mental health problem

◆ ABC charts

Antecedent/behaviour/consequence (ABC) charts can be structured to record incidences of any behaviour, not only aggression. They offer an opportunity to identify why particular behaviour might occur, by recording behaviour before, during and after an incident. As well as potentially identifying triggers and functions of behaviour, they also allow us to evaluate how an incident was managed or resolved.

Specific assessment tools

For many people with learning disabilities, the use of standardised mental health/behavioural assessment tools may not be appropriate. Some instruments have been designed specifically for people with learning disabilities:

◆ Assessment of Dual Diagnosis (ADD)

Provides information on diagnosis, developing treatment plans and evaluating outcomes (Matson and Bamburg, 1998).

◆ Camberwell Assessment of Need for Adults with Developmental and/or Intellectual Disability (CANDID) (Adults)

This is a semi-structured interview developed to assess need in people with learning disabilities (Xenitidis et al, 2003).

◆ **Cardinal Needs Schedule – Learning Disability Version (LDCNS)**

Systematic process of needs assessment covering 23 areas of functioning (Raghavan et al, 2004).

◆ **Diagnostic Assessment of the Severely Handicapped (DASH)**

96-item informant rating scale, based on DSM-IV-TR diagnostic structure, for use with adults with severe to profound learning disabilities (Matson, Coe, Gardner & Sovner, 1991).

◆ **Health of the National Outcome Scale for people with Learning Disabilities (HoNOS-LD)**

HoNOS-LD can be used by a range of professionals including psychiatrists, psychologists and behavioural support workers. It does not replace diagnostic tools, but provides a useful way of assessing global changes in people undergoing treatment (Roy et al, 2002).

◆ **Psychiatric assessment Schedule for Adults with Developmental Disabilities (PAS-ADD)**

This comes in different formats; there is the semi-structured interview for professional staff that assesses mental state, and a checklist version for carers and support staff of potential indicators of mental health problems (Moss, 2002).

◆ **Psychopathology Instrument for Mentally Retarded Adults (PIMRA)**

A rating scale that can be completed by third party informants and self-report (Matson, 1988).

◆ **Reiss Screen for Maladaptive Behaviour (Adolescents and Adults)**

38-item scale to be completed by carers or support staff. Applicable to all people with learning disabilities (Reiss, 1997)

Risk assessment and management

The assessment and management of risk is a core component of any mental health assessment and care plan, and is just as significant for people with learning disabilities. You should apply standard risk assessment, paying particular attention to certain issues.

◆ **Suicide and self-harm**

Episodes of self-harm are less severe and suicidal attempts less frequent in people with learning disabilities compared to the wider population. Nevertheless, apparent attempts should not be disregarded. Sometimes clinicians may consider as insignificant an attempt at self-harm or suicide which was observed or reported by the individual, perhaps attributing it to attention seeking. However, these attempts may be more serious than they appear, because an individual may lack the knowledge or ability to carry out what feels to them a genuine act of self-harm or suicidal attempt. For example, a person with learning disabilities may take two paracetamol and report it as a suicide attempt. Though they are unharmed, there was intent to harm, and the individual is experiencing severe emotional distress. They may not have known what is a harmful dose of paracetamol and could take more next time.

◆ **Vulnerability in mainstream mental health services**

Some people with learning disabilities may be vulnerable when they use mainstream mental health services. Vulnerability can include all kinds of abuse and exploitation. Regardless of their level of ability, anyone can be vulnerable in a mental health care setting, so you should consider for users with learning disabilities how you manage risk for other service-users, such as those in catatonic states. When the risk cannot be managed, it may be more appropriate for the individual to use specialist learning disability services. However, it is important to assess the risk of vulnerability for each individual. The term 'learning disabilities' should not be used as basis for exclusion – when exclusion is based on disability and not need, it becomes discrimination.

◆ **Protection not exclusion**

Risk assessment and management can sometimes be used as a mechanism to stop people with learning disabilities from having life experiences that the wider population take for granted. Risk assessment should be used to protect individuals from potential harm, but also as a way of identifying what is needed to improve their quality of life. People with learning disabilities have the right to make their own decisions. If their capacity is questioned, you should make every effort to support them in making a decision, even if it seems unwise to others.

7

Presentation of mental health problems

The way mental health problems present in people with learning disabilities can make the assessment process more difficult. Some signs and symptoms may appear atypically or be overshadowed by conditions such as autism.

Some clusters of symptoms may allude to a particular condition in an individual, though they do not meet full diagnostic criteria. This can lead clinicians to diagnose an unspecified disorder rather than make a more specific diagnosis – for example, diagnosing ‘personality disorder unspecified’ rather than an exact category, or ‘psychotic illness’ instead of a subtype of schizophrenia.

This section discusses the prevalence of data for different mental health problems among people with learning disabilities, and describes how the conditions present.

At the end of the section, Box 6 is a case study of how a man with learning disabilities experiences mental health problems, and how the different services try to diagnose the problem.

Attention deficit hyperactive disorder (ADHD)

Levels of ADHD are higher in people with learning disabilities, with 3% of those with borderline and 12% of those with mild learning disabilities reported to have ADHD (O'Brien, 2000). This figure may be higher still, but may be misdiagnosed as personality disorders or as bipolar affective disorder (Spenser et al, 1994). The reasons for higher levels of ADHD could be that adults with learning disabilities are at a developmental stage where the symptoms of ADHD are particularly prevalent.

Affective disorders

The reported prevalence rate of affective disorders in people with learning disabilities varies widely, but a recent study found the overall prevalence of these disorders to be 6.6% (Cooper et al, 2007). There is a lack of research showing how the rates of affective disorders vary between people with mild and severe learning disabilities.

◆ Depression

In people with mild learning disabilities who have good

communication skills, and can recognise and articulate their emotions, similar assessment methods are used as those for the wider population. Where an individual does not self-report their symptoms, we have to rely on behavioural signs for diagnosis. As well as weight loss, which we might expect to see in depression, people with learning disabilities may present atypically with an increased appetite and subsequent weight gain.

Staff may not report on other symptoms such as social withdrawal, because they do not identify them as a problem. Typical changes associated with depression in personal hygiene and appearance may not be so prominent when people have regular support from carers.

◆ Bipolar disorder

Bipolar disorder is estimated to be higher in people with learning disabilities. Deb and Hunter (1991) observed cyclical changes in behaviour in 4% of people with learning disabilities. The gender ratio of bipolar disorder is equal in people with learning disabilities, compared to the higher numbers seen in women in the general population (Vanstraelen and Tyrer, 1999).

Changes in activity levels, appetite and sleep can be observed in people with learning disabilities, but their grandiose delusions are likely to be less expansive.

Rapid cycling bipolar disorder is more common in people with learning disabilities. It is associated with brain injury and abnormal EEG findings.

Anxiety

There is a great deal of variation in the reported prevalence rates of anxiety disorders, although the incidence is thought to be higher in people with learning disabilities; a recent study reported a rate of 3.8% (Cooper et al, 2007). Anxiety disorders are seen in equal proportions in both genders of people with learning disability, compared with the wider population where incidence is higher in women.

The presentation of anxiety disorders can differ in people with learning disabilities. Sometimes their inability to describe accurately their internal symptoms means they describe their mental distress as physical illness, such as stomach pains or headaches. When an accurate self-report is unavailable, we need to observe

for behavioural signs of acute anxiety or sleep disturbance.

We may not notice problems like social phobias if a person has a restrictive environment, is under close supervision or receives support when they are in the community.

Anxiety may also be a symptom of another mental health problem, such as depression or psychosis, which has gone undiagnosed.

Delirium

There are no exact prevalence figures for delirium in people with learning disabilities. This condition can go undetected or misdiagnosed as psychotic illness.

Delirium may present more frequently in people with learning disabilities due to the increased risk of infections seen in this group. There is also a risk of toxic reaction due to the introduction of, or changes in, medications, especially in people with metabolic disorders.

Dementia

Higher prevalence rates of dementia exist in people with learning disabilities: 21.6 % compared with 5.7 % in those above 65 years (Cooper, 1997). The prevalence of dementia is further increased in people with Down's syndrome, where Alzheimer's disease is seen in much higher rates and at an earlier age.

Dementia may progress more rapidly in people with learning disabilities, although this could also be because early symptoms go unnoticed in people whose routines such as hygiene and dressing are supported anyway by a carer.

It is difficult to observe for a decline in skills, memory and orientation without knowing the individual's premorbid abilities. Having a baseline of skills and functioning is advantageous, as are early screening assessments, especially for people particularly at risk (e.g. people with Down's syndrome).

Eating disorders

Anorexia nervosa and bulimia are less common in people with learning disabilities than in the wider population, but hyperphagia and pica are more prevalent. However, in people with mild learning disabilities, prevalence rates may be similar to those seen in the wider population.

Weight loss may not always be indicative of an eating disorder and may be a symptom of another mental health problem such as depression or a physical health problem. Diagnosis of bulimia or anorexia nervosa will rely on the individual reporting their subjective experiences of distorted body image, which requires relatively sophisticated verbal skills. Over eating is particularly associated with Prader-Willi syndrome.

Obsessive Compulsive Disorder (OCD)

The prevalence of OCD in people with learning disabilities is thought to be 3.5% (Vitello et al, 1989). It is difficult to give a clear diagnosis of OCD without the person demonstrating a subjective struggle not to carry out the compulsion. For some, carrying out what looks like a compulsion may be a pleasurable activity.

It may also be difficult to differentiate between a true compulsion and stereotyped movements, mannerisms or complex tics. Compulsions and stereotypic behaviour are often seen in people with autism and may distort the diagnostic picture.

Personality Disorder

Giving a diagnosis of personality disorder in people with learning disabilities is a contentious issue, with some clinicians arguing that it is unfair or improper to use this diagnosis in this population, especially in people with more severe learning disabilities. Some clinicians may delay giving a diagnosis until an older age than they would for the wider population, to account for a longer developmental period in someone with learning disabilities.

Personality disorders are considered to be more prevalent in people with learning disabilities, though it is often difficult to subdivide personality disorders into different groups. Cooper et al (2007) found a prevalence of 1%.

Before giving a diagnosis of personality disorder, clinicians must take into account an individual's circumstances and conditions such as autism. For example, people with autistic spectrum disorders may appear to have anankastic personality traits. An anti-social personality disorder may also be attributed to someone with autism if they have not developed 'theory of mind', and may lack empathy.

Post Traumatic Stress Disorder (PTSD)

There is little research on PTSD in people with learning disabilities. We can assume that people with learning

disabilities can develop PTSD just as they can develop other mental health problems, and given the high levels of neglect and abuse that people with learning disabilities often suffer. PTSD may present as aggression or occur co-morbidly with other mental health problems.

Psychotic Illness

Non-affective psychotic disorders have a raised prevalence in people with learning disabilities. Hatton (2002) found rates of between 2-6% when examining prevalence figures. Cooper et al (2007) found a prevalence of 4.4% for the range of psychotic disorders. People with learning disabilities are less likely to use illegal psycho-active drugs, so induced psychosis is not as commonly seen as in the wider population.

People with learning difficulties may find it difficult to report their hallucinations and describe delusional beliefs. Without good communication skills, it is difficult to know whether the person is experiencing hallucinations or delusional beliefs.

People with mild learning disabilities can be assessed in much the same way as people without learning disabilities. You can apply standardised ICD-10 diagnostic criteria to this group.

Some people may show behaviours that leads observers to believe wrongly that an individual is responding to hallucinations. For example, the echoed speech seen in people with autism may give the impression they are holding a conversation, when in fact they are repeating fragments of speech they heard earlier.

Schizophrenia

The prevalence of schizophrenia has been found to be three times that of the wider population, with Deb et al (2001) reporting that the prevalence rate lies between 1.3% and 3.7%. The onset of schizophrenia has an earlier onset of 22.5 years in people with learning disabilities compared to 26.6 years in the wider population (Meadows, et al. 1991).

Like all psychotic illness, a diagnosis of schizophrenia is difficult in people with severe/profound learning disabilities and reduced communication skills.

Delusions in people with learning disabilities tend to be less complex and involved than those found in the wider population, because the delusions are drawn from the person's more limited field of experience. For example,

delusions concerning the internet, satellites and spy networks will not appear if the person has no experience of these.

You need to examine ideas of victimisation for any basis in truth. People with learning disabilities may well have been victimised because they are 'different' and they may be right if they feel people are trying to harm them.

Hallucinations tend to be simple. People with learning disabilities are less likely to have thought echo, second person hallucinations and running commentary.

A decline in someone's social functioning and self help skills may be masked if they receive support from carers. Even when symptoms such as poor hygiene or a lack of self-help skills are identified, the assessor could attribute them purely to the individual's learning disabilities, and steer away from a diagnosis of schizophrenia.

Behaviours seen in people with autism may be similar to those we see in people with schizophrenia. For example, neologisms are also seen in autism as are bizarre motor mannerisms.

Many people do not demonstrate a sufficient range of symptoms to meet standard criteria (ICD-10) for schizophrenia, so assessors may use a diagnosis of 'psychotic episode'.

Substance misuse

Levels of drugs and alcohol misuse are lower than in people without learning disabilities, but are an emerging issue of concern. Drug and alcohol misuse are less likely in supported environments where support staff are involved in an individual's social life, where tenancy agreements require a code of conduct from tenants, or where money is under the supervision of carers.

People with learning disabilities living in more independent settings may have access to alcohol, but be restricted by lack of income. They may also have knowledge of drugs but lack the social skills required for their purchase.

This does not mean that substance misuse should be discounted. A small but increasing number of people with learning disabilities living independently can and do develop substance misuse problems, and are sometimes targeted due to their vulnerability.

Box 6**Positive practice example: Diagnosing Tom's problems****Tom**

Tom is a 25-year-old man who has learning disabilities, epilepsy and autism. He lives in a ground floor flat and receives two hours outreach support three times a week from a local voluntary service. He attends computer classes at a local college and does work experience in a local café one day a week. He doesn't have many friends, but does enjoy socialising. He finds it difficult to understand the subtle rules of interaction and is often seen as rude. Tom's interests include reading science fiction books and comics and watching horror movies. Tom has a social worker, who works in the local community learning disability team (CLDT), whom he sees once a year for a review. He has attended a social skills group in the past run by the speech and language therapy team at the CLDT.

Change in behaviour

Four months ago, Tom was mugged on his way home from college. He was not physically injured, but the incident left him very shaken. Since then, outreach staff have seen a gradual decline in his overall well-being. He took two weeks off college and work immediately after the attack, but his attendance since has been sporadic. His interest in his appearance and flat has decreased, though his interest in watching horror films has increased. It seems to the staff that this is all he does. His keyworker suggested that he visit his GP to see if he could be referred to a counsellor, but he refused.

Over the last week, Tom's behaviour has become even more out of character. An agency support staff member saw him appearing to be role-playing scenes from his favourite horror films and talking to different characters. He has also referred to some of the outreach staff as vampires and monsters. After a week's annual leave, Tom's keyworker returns to find that his flat is flooded and after Tom lets her in, he barricades himself in his bedroom. She immediately calls his social worker.

After visiting Tom, the social worker arranged for the consultant psychiatrist from the CLDT and an Approved Social Worker (ASW) from the community mental health team to assess him. They persuaded him to come into the local, adult

mental health inpatient ward. On admission, Tom said he wanted to leave and that he would not let anyone near him or into his flat. The staff team decided to admit him under Section 2 of the Mental Health Act (1983) and detained him for a period of assessment.

Key points about the assessment process

- During the assessment on the ward, the psychiatrist and nursing team found it quite difficult to understand information from Tom. On occasion, he would say phrases that were out of context or use words that they had never heard before. They thought this could be a symptom of psychosis, but after interviewing his keyworker they established that Tom was echoing what he had heard in a previous conversation and he had a history of using 'neologisms' (inventing his own words), both of which are a common features of autism.
- During the history taking, the team noted that Tom had never previously been known to act out scenes or fantasies. When they asked him about the incident at home, he described the staff team as "vampires, who are out to kill me". He was unable to elaborate on this belief, but it was unshakeable. It did not fit his developmental level and previous behaviour, and the team concluded that Tom was likely to be experiencing paranoid delusions. He said voices were telling him to be wary of the vampires, but he was unable to give any further information about the voices. The team suspected that he was experiencing auditory hallucinations.
- The ward team had little experience of people with learning disabilities and/or autistic spectrum disorders. The ward manager arranged for a community learning disability nurse and a speech and language therapist to give a training session on these issues.
- Tom's keyworker provided a lot of information for the assessment, but also on general support issues. Tom had a Personal Health Profile, which she had developed in collaboration with the CLDT, which provided information on Tom and his needs and was given to the ward.
- After a three week assessment period, Tom was diagnosed with acute psychotic episode.

8

Interventions

People with learning disabilities are entitled to, and can benefit from, the full range of interventions available to people with mental health problems. Some interventions may need adaptation to the individual's level of ability. Interventions can be divided for simplicity into three broad categories

- ◆ social, such as community integration programmes and support with social issues
- ◆ psychological, such as cognitive behavioural therapy (CBT), psychotherapy and counselling
- ◆ biological or physical, such as psychopharmacotherapy

Social interventions and relapse prevention

The aim of social interventions is twofold:

- ◆ to reduce the factors that made the individual vulnerable to developing a mental health problem (see Section 5)
- ◆ to support them in increasing factors that will protect them from relapse or reduce its likelihood (protective factors are listed in Box 7).

As they would for the wider population, support teams will often need to address issues such as accommodation, finances, social networks and employment or meaningful daytime activity.

Support teams need to help the person recognise and understand potential triggers or stressful situations, particularly times of loss or transition. This will help the individual to implement their own coping strategies and/or alert carers or support services. For example, teaching an individual to recognise the symptoms of anxiety they get before a panic attack and to develop a plan of self-intervention for these times – as Box 8 shows in detail.

This approach can be used in a number of situations both to help the individual control their symptoms and to prevent escalation. As well as looking at physiological symptoms, you can use thoughts and feelings that occur

Box 7

Possible protective factors for people with learning disabilities

Adapted from Hardy et al 2006.

- ◆ Improving physical health
- ◆ Feeling secure and safe from harm
- ◆ Being given choice and control over one's life
- ◆ Developing assertiveness and communication skills
- ◆ Building social networks
- ◆ Developing coping skills
- ◆ Having employment and meaningful daytime activities
- ◆ Having responsibility and recognising achievement
- ◆ Being supported through change and transition
- ◆ Being supported in a person-centred way
- ◆ Having access to support services
- ◆ Having one's various needs recognised and met.

prior to distressing events to educate and devise coping strategies.

Psychological interventions

Until relatively recently, psychological therapies were rarely used with people who have learning disabilities. Professionals often felt psychological interventions were not beneficial as individuals lacked the intellectual and communication ability to partake in therapy. But with flexible and adapted implementation of psychological treatments, people with learning disabilities not only do benefit from these treatments, but can use the techniques to promote mental well being. Examples include the use of psychodynamic psychotherapy, systemic therapy and counselling. Group therapy, using a range of psychological models, can also be beneficial.

Box 8**Example of an anxiety management programme****Stage 1: Recognise change**

My pulse rate increases, become sweaty and restless, mouth becomes dry

Stage 2: Being aware of what happens next

When I feel like this, I may find it difficult to breathe, I may panic and collapse

Stage 3: How can I stop it?

By using coping strategies, e.g. controlling breathing, thinking pleasant thoughts, listening to a relaxing tape, telling myself calmly this has happened before and I will be alright

Stage 4: Letting someone know

Recording or telling someone what happened, how I coped and if it worked.

Two commonly used approaches are behavioural interventions and cognitive behaviour therapy.

Behavioural interventions

These approaches have had success in people who have higher support needs, by providing a consistent approach and positive reinforcement for pro-social behaviours, with negative behaviours not reinforced. The approach emphasises finding the function of a behaviour and supporting the individual in replacing it with more appropriate behaviour. These techniques still require the person's involvement, so where possible they understand the plan, know what the goals and targets are, how their behaviour will be managed and what the benefits of change are.

Cognitive behaviour therapy (CBT)

CBT may take longer to implement, as concepts require explanation, getting ready for sessions may need more preparation and homework may need carer support. In getting people to write diaries or complete rating scales, therapists may need to give examples and present materials in a format the individual can understand, including audio or video recordings. To make information accessible, some people may benefit from the use of pictorial representation but other people with learning disabilities may find this childish and even

offensive. The choice of materials will depend on what helps the individual to understand and focus on the relevant information and feel an equal partner in the therapeutic relationship.

Biological and physical interventions

Psychotropic medication should always be given to someone with caution, regardless of their ability. In the past, there was widespread concern about the use of psychotropic medication for people with learning disabilities. Concerns included:

- ◆ high rates of prescription, 30%-75% of people with learning disabilities
- ◆ whether medication is used for reasons other than its indicators
- ◆ polypharmacy – people in receipt of two or more psychotropic medication
- ◆ lack of evidence for efficacy
- ◆ little or no review
- ◆ medication given when there is often no clear diagnosis.

(Emerson 1997, Kroese et al, 2001, Chapman et al, 2006)

With the introduction of clinical guidelines, improved diagnostic techniques and increased emphasis on positive behavioural management, the use of psychotropics has decreased (Holden and Gitlesen, 2004). Studies in the UK in the 1990s, showed prescription rates to be between 11% – 32% (Brandford et al, 1995). Studies have shown the efficacy of medication for people with learning disabilities to be the same as for the wider population (Clarke 1999).

Sturmey (1999) offers some guidance on ethical prescribing for people with learning disabilities:

- ◆ for people with mild learning disabilities, there should be a clear diagnosis from a recognised classification system and the medication should be indicated for that diagnosis
- ◆ for people with severe learning disabilities, there should be a clear, substantiated diagnostic hypothesis and the medication should correspond to that hypothesis.

Clinicians prescribing medicines must consider and weigh up potential side effects against potential benefits. It has been suggested that people with learning disabilities, particularly people with existing epilepsy and movement disorders, are more susceptible to the side effects of psychotropics. So individuals should be started on a lower dose, and carefully observed for side effects, as some patients may not be able to describe any side effects they are experiencing. Clinicians must be aware of potential interaction of drugs in individuals who are receiving multiple medications for other physical and neurological conditions.

Psychotropic medication should be used only as part of an overall care package that is subject to regular review and scrutiny. As well as feedback on its efficacy from people themselves, the clinical team should use published or clinician-designed rating scales for evaluation.

Medicines in controlling behaviour

One of the most controversial uses of medication is to control behaviour. Whilst rapid tranquillisation is an accepted part of emergency mental health care, its use to alleviate behavioural problems is not. Deb et al (2006) have recently published good practice guidelines on these issues. Clinical teams should be wary of using medication to control someone's challenging behaviour. If medication is used, it should be part of the individual's overall care plan, with emphasis placed on supporting the individual to develop appropriate behaviours and skills, rather than relying on medication.

If the person is not detained under mental health legislation, the guidelines laid out in capacity law should be strictly adhered to – as with all treatments, the person's informed consent is required before they are given medication. Medication information resources developed for people with learning disabilities are listed in Section 9.

Monitoring and evaluation

There are various approaches to monitoring the efficacy of treatment.

One method is to ask the person to rate symptoms on a scale. To help conceptualise a scale for those who have difficulty in understanding the idea, you can use everyday objects such as a thermometer, traffic lights or

a range of faces showing different emotions. Another method is to use a diary. These can be used to give a valuable insight into the individual's perception of their experience, for instance when they feel down, angry, or experience unusual thoughts.

A holistic approach

As in most mental health practice, a single approach will rarely provide all the answers to someone's problems. Interventions need to complement each other. Unfortunately, people with learning disabilities are still likely to receive more physical treatments and fewer psychological treatments than others accessing mainstream services.

The principles in treating this group of people are among the basic tenets of the recovery model outlined in the Chief Nursing Officers Report on Mental health Nursing (DH, 2006). They are: to make the experience meaningful, to be driven by each individual's needs, and to promote inclusion.

Box 9**Positive practice example : Treating Tom's problems**

Tom was diagnosed as having an acute psychotic episode. His insight about his condition was still poor and he made it clear that he would leave the ward as soon as he could. He was transferred from a Section 2 to a Section 3 under the Mental Health Act. Shortly after being admitted, he was prescribed an anti-psychotic medication, Risperidone.

Key points about the interventions and aftercare:

- some of the ward staff thought that Tom should be detained under the category of 'mild mental impairment'. The consultant psychiatrist disagreed – as Tom had a clear, diagnosed mental health problem, the more appropriate category would be 'mental illness'
- though consent was not required under the Mental Health Act, Tom's primary nurse obtained some accessible information about the drug Risperidone and talked through it with Tom
- Tom was started on a low dose of Risperidone, to minimise side effects as he has epilepsy
- within a few weeks of Tom's admission to the ward, the nursing team noted that he regularly became anxious. After discussion with his outreach keyworker, they concluded that life was too unpredictable on the ward for Tom and that he needed more structure. They created a pictorial timetable which highlighted the main activities on the ward such as mealtimes, ward rounds, group activities and visiting times, so that Tom could understand what was happening. The team tried to make things as predictable as possible for him.
- a referral was made to the psychology and psychiatry teams of the CLDT, so that they would be able to work with Tom on his discharge. The CLDT psychology team began work with Tom. After the assessment, they made plans with Tom that when he was discharged they would offer him counselling to address his recent attack and the losses in his life. They would also help him with stress management. The CLDT allocated Tom a consultant psychiatrist and a community learning disability nurse
- within a few months, Tom was nearer his old self. He was no longer experiencing psychotic symptoms and was functioning at his pre-morbid level. He was very eager to return home and to his usual routine
- at the Section 117 meeting it was agreed that Tom would leave the ward, under Enhanced Level CPA. The community learning disability nurse would be Tom's care co-ordinator
- Tom's primary nurse and one of the psychiatrists trained the outreach team in recognising Tom's potential triggers for, and signs of, relapse. With Tom's agreement, the psychologist discussed with the team the stress management plan and how they could support Tom
- Tom continued to take Risperidone. After a year of being symptom free, the medication was gradually reduced. He has continued to implement his coping and stress management strategies.

References and resources

Classification systems

National Association for the Dually Diagnosed

The DM-ID: A Clinical Guide for the Diagnosis of Mental Disorders in Persons with Intellectual Disabilities, available from The National Association for the Dually Diagnosed, at www.thenadd.org

Royal College of Psychiatrists

DC-LD (Diagnostic criteria for psychiatric disorders for use with adults with learning disabilities/mental retardation), available from Royal College of Psychiatrists/Gaskell Publishing, at www.rcpsych.ac.uk

World Health Organisation

ICD-10 Guide for Mental Retardation, available to download from www.who.int

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Journals

Advances in Mental Health and Learning Disabilities
Available from www.pavpub.com

Journal of Mental Health Research in Intellectual Disabilities
Available from www.thenadd.org

Training resources for staff

Down's syndrome and dementia resource
Dodd K, Turk V and Christmas M (2002) British Institute of Learning Disabilities (www.bild.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)

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)

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)

Meeting the emotional needs of young people with learning disabilities: a booklet for parents and carers

Wertheimer A (2003)

Foundation for people with learning disabilities (www.learningdisabilities.org.uk)

What's happening?

(DVD where three young people with learning disabilities talk about feeling anxious and depressed and what helped them start to feel better)

University of Strathclyde (2006)

Foundation for People with Learning Disabilities (www.learningdisabilities.org.uk)

Useful organisations

Learning disability email networks

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

Useful Learning Disability Organisations

British Institute of Learning Disabilities (BILD)

Organisation that provides research and training on a wide range of issues affecting people with a learning disability. www.bild.org.uk

Estia Centre

Organisation that specialises in the mental health needs of people with a learning disability. Provides training, research and development. www.estiacentre.org

Elfrida Society

Organisation that researches better ways of supporting people with a learning disability. Provides a wide range of accessible information on health issues. www.elfrida.com

Foundation for People with Learning Disabilities

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

Mencap

National organisation that fights for equal rights and greater opportunities for people with a learning disability. www.mencap.org.uk

National Development Team

Organisation that works to improve policies, services and opportunities for people who are disadvantaged, including people with a learning disability. www.ndt.org.uk

Nora Fry Research Centre

Organisation whose interests are evaluation and development of services for people with a learning disability.

www.bris.ac.uk/Depts/NorahFry

Scottish Consortium for Learning Disabilities

Organisation made up of 13 partner organisations that offer advice, support and consultancy to services around Scottish policy on learning disability.

www.sclld.org.uk

Tizard Centre

Organisation that provides research and development in community care, especially for people with a learning disability and challenging behaviour.

www.kent.ac.uk/tizard

Welsh Centre for Learning Disabilities

Organisation that provides research, development and training into the well being of people with a learning disability.

www.cardiff.ac.uk/medicine/psychological_medicine/research/welsh_centre_learning_disabilities

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

Care and Treatment of Offenders with Learning Disabilities

Provides information on people with learning disabilities who have or are at risk of committing offences.

www.ldoffenders.co.uk

Challenging Behaviour Foundation

Provides guidance and information on supporting people with challenging behaviour, including fact sheets.

www.thecbf.org.uk

Down's syndrome Association

www.dsa-uk.com

Easy Info (how to make information accessible)

Provides guidance on how to make information accessible.

www.easyinfo.org.uk

Fragile X Society

www.fragilex.org.uk

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

Mencap's Guidance on Making Information Accessible

Guidance on how to make information accessible.

www.mencap.org.uk/html/accessibility/accessibility_guides.htm

National Association for the Dually Diagnosed

(USA organisation dedicated to the mental health needs of people with a learning disability)

www.thenadd.org

National Attention Deficit Disorder Information & Support Service (ADDISS)

www.addiss.co.uk

National Autistic Society

www.nas.org.uk

People First

A national self advocacy organisation run by people with learning difficulties for people with learning difficulties.

www.peoplefirstltd.com

Prader-Willi Association UK

www.pwsa.co.uk

Royal College of Nursing

www.rcn.org.uk

Royal National Institute for the Blind

www.rnib.org.uk

Royal National Institute for the Deaf

www.rnid.org.uk

Scope

Organisation that promotes equal rights and improved quality of life for disabled people, especially those with cerebral palsy.

www.scope.org.uk

Tuberous Sclerosis Association

www.tuberous-sclerosis.org

Turner's Syndrome UK

www.tss.org.uk

Valuing People Support Team

English 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

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The leading journal in mental health nursing

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