

Learning Disability Today

4th
Edition

**The essential guide for support staff,
service providers, families and students**

Edited by

Eddie Chaplin, with Marian Jennings,
Gill Concannon, Renee Francis,
Jo Delree and Lesley Bedford



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Contents

About the contributors.....	v
Foreword.....	xii
Introduction	1
Section 1: It's my life	
Chapter 1: What does having a learning disability mean to us?	9
Chapter 2: Positive Behavioural Support – enhancing quality of life for people with learning disabilities whose behaviour is considered challenging	15
Chapter 3: Communication	27
Chapter 4: From advocacy to involvement to co-production and back again.....	39
Chapter 5: Sexuality and relationships education for people with learning disabilities	47
Section 2: Staying healthy	
Chapter 6: Health promotion and supporting people to access mental and physical health services	57
Chapter 7: Physical health.....	69
Chapter 8: Mental health	85
Section 3: Topical issues	
Chapter 9: Dementia in people with learning disability	105
Chapter 10: Autism	113

Chapter 11:
Supporting people with profound and multiple disabilities 131

Chapter 12:
Supporting people with learning disabilities at the end of life 139

Section 4: Staying safe

Chapter 13:
Safeguarding adults with learning disabilities: what is abuse? 151

Chapter 14:
Safeguarding adults with learning disabilities
– what to do and how to prevent abuse 165

Chapter 15:
Positive risk-taking – supporting people with learning
disabilities to live a life like any other..... 177

Chapter 16:
Hate crime – crime against disabled people..... 191

Chapter 17:
People with learning disabilities in the Criminal Justice System 201

Further Resources 211

Chapter 8:

Mental health

By Karina Marshall-Tate and Eddie Chaplin

Aims

- To understand mental health and how to promote mental well-being.
- To recognise symptoms of poor mental health and how this can present in people with learning disabilities.
- To understand common mental illnesses.
- To understand the support needs of people with common mental illnesses.

Summary

Mental health and physical health are linked and dependant on each other. Mental health, like physical health, is therefore essential to our well-being. This chapter introduces mental health and how we can spot common mental illnesses. It also aims to show how we can support people with a learning disability to achieve good mental health.

Introduction

In this chapter, we will explore what mental health is, why it is important for people with a learning disability, and the role that support staff and/or family carers can play in supporting individuals to maintain their mental health and well-being. Finally, we will look at some of the warning signs that could indicate that someone is experiencing mental health difficulties, what we can do to support that person, and how to get help.

What is mental health?

Mental health, or mental well-being, is a state of health that enables us to live fulfilled lives and cope with everyday stressors. It is not merely about the absence of mental illness, but about our whole being.

We all have mental health and we can all experience periods of mental ill health. This can be in relation to life events, such as loss and bereavement, stress or relationship difficulties, or there can be no identifiable cause. Some mental health difficulties can be linked to specific episodes of mental illness such as depression or psychosis. In all cases, the way that people experience mental health and mental illness is different and it can vary over their lifespan. For example, a person with schizophrenia will be able to lead an ordinary life when they are mentally well but may require periods of health care while unwell.

People with learning disabilities, like the wider population, can experience periods of mental health difficulties or mental ill health. However, it is only over the last 30 years that health staff have acknowledged this and it is only recently that mental health and well-being for people with a learning disability as well as the wider population has been recognised as a significant factor in public health, health service planning and delivery.

Mental health and well-being

There has been a significant shift in attitudes toward mental health recently. The Duke and Duchess of Cambridge, and Prince Harry, are actively promoting mental health to combat stigma and encourage open dialogue about mental health issues through their 'Heads Together' campaign². The government has publicly committed to removing injustices in mental health care and improving mental health services in the NHS (HM Government, 2017), and many celebrities have spoken openly about their mental health difficulties. The NHS has promoted mental health and well-being with the 'Five Ways to Wellbeing' initiative (HM Government, 2008). The research that underpinned this initiative found that small changes to our daily lives can have a significant impact on our mental health and well-being and help people to flourish.

Breaking down stigma and promoting mental health will have huge benefits and *must* be inclusive of people with learning disabilities.

2 For more information, visit www.headstogether.org.uk

The 'Five Ways to Wellbeing' are:

Connect...	With the people around you. With family, friends, colleagues and neighbours. At home, work, school or in your local community. Think of these as the cornerstones of your life and invest time in developing them. Building these connections will support and enrich you every day.
Be active...	Go for a walk or run. Step outside. Cycle. Play a game. Garden. Dance. Exercising makes you feel good. Most importantly, discover a physical activity you enjoy and that suits your level of mobility and fitness.
Take notice...	Be curious. Catch sight of the beautiful. Remark on the unusual. Notice the changing seasons. Savour the moment, whether you are walking to work, eating lunch or talking to friends. Be aware of the world around you and what you are feeling. Reflecting on your experiences will help you appreciate what matters to you.
Keep learning...	Try something new. Rediscover an old interest. Sign up for that course. Take on a different responsibility at work. Fix a bike. Learn to play an instrument or how to cook your favourite food. Set a challenge you will enjoy achieving. Learning new things will make you more confident as well as being fun.
Give...	Do something nice for a friend, or a stranger. Thank someone. Smile. Volunteer your time. Join a community group. Look out, as well as in. Seeing yourself, and your happiness, linked to the wider community can be incredibly rewarding and creates connections with the people around you.

(HM Government, 2008)

These five ways are no different for people with learning disabilities, however carers and/or family members may have to support an individual to achieve them as some people with a learning disability can experience significant barriers in trying achieving them. Historically, social exclusion and institutionalisation prevented access to such initiatives, and latterly, community access and community participation remains a challenge for some people with a learning disability and their family and carers. Contemporary approaches to care and support such as active support, person centred care and positive behaviour support can work in parallel with the Five Ways to Wellbeing, and indeed they share common themes. By incorporating the Five Ways into care and support practices, support workers, carers and family carers can help to promote the

mental health and well-being of people with a learning disability. These do not have to be grand gestures, such as volunteering, but can be simple things that can be achieved daily, like taking time to notice the world around us or smiling and saying good morning to our neighbours as a way of connecting with others.

Case study: Supporting mental health with the Five Ways to Wellbeing

Akinwale lives in supported accommodation with three other men and a team of support workers. He had a good relationship with Kevin, the area manager, and they enjoy playing football and computer games together. Unfortunately, Kevin was transferred to a new location and Akinwale was no longer able to see him. After a couple of weeks, the remaining staff and Akinwale's housemates noticed that he was more quiet than usual and that, although he still participated in activities with them, he did not seem as interested or to be enjoying them as much. Akinwale told them that he missed Kevin and felt sad and lonely. The staff and housemates decided to use the Five Ways to support Akinwale while he experienced these mental health difficulties. They supported him to connect with Kevin by sending him a postcard; they helped him to be more active by encouraging him to try new activities; and they helped him by showing his housemates how to play the computer games that he used to play with Kevin. Gradually, Akinwale began to return to his normal self and was able to adjust to his new circumstances.

The mental health needs of people with a learning disability

People with a learning disability can experience higher rates of mental health difficulties and mental illness than the wider population. The reasons for this are varied and complex but can be broadly categorised in three ways: predisposing, precipitating and perpetuating factors. That is, factors that make people more vulnerable to developing a mental illness, factors that trigger a mental illness, and factors that maintain or exacerbate mental health difficulties. These factors can be broken down further into biological, psychological and social vulnerabilities (see Table 1). Life events, such as bereavement, bullying, stress and problems at work, can also affect our mental health.

Predisposing factors to poor mental health

Biological	Genetic syndromes such as Prader-Willi, Lesch Nyhan or DiGeorge Epilepsy Some medications Brain damage Physical health conditions
Psychological	Poor problem solving or coping skills Difficulties recognising and communicating thoughts, feelings and distress
Social	Isolation Social exclusion Deprivation Unemployment Poor housing

(Adapted from Chaplin *et al*, 2016)

People with a learning disability are more likely to experience these precipitating, predisposing and perpetuating factors than the wider population, and therefore have higher rates of mental illness. When a person with a learning disability experiences mental health difficulties they are also more likely to be hospitalised out of area – that is, far from their home and family and carers – and they are more likely to be prescribed higher rates of psychotropic medications (medicines to treat mental illnesses). These medications can help people experiencing mental illnesses such as schizophrenia, bipolar disorder or severe depression, however they have also been prescribed as a way to ‘manage’ challenging behaviour in the absence of a mental illness in people with a learning disability³.

However, there is no evidence of their efficacy in treating challenging behaviour, although their short-term use to manage an acute episode of violent or dangerous behaviour is commonly accepted practice. In some cases, medication can also have debilitating side effects for some people and so the prescription of such medicines

³ For more information, see the NHS STOMP campaign: <https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/>

needs to be made after careful and extensive assessment by an experienced clinician (RCP, 2016).

Mental health promotion and mental well-being should therefore be a significant factor in care and support plans to promote resilience and coping strategies, to reduce the impact of potential stressors, and to reduce a person's vulnerability to developing mental health difficulties.

Recognising and responding to concerns about mental health

When our mental health and well-being is vulnerable, we may see changes in the way that we think, act and do things. For example, we may interpret things in negative ways, we may change our behaviour by not doing things that we used to, or by doing new things to try and block out difficult feelings – like using illicit drugs or alcohol – or our motivation to do things may change. Other signs that someone may be experiencing mental health difficulties include:

- Changes in sleep pattern.
- Changes in appetite.
- Withdrawal and self-isolation.
- Increased use of alcohol or drugs.
- Headaches, neck and shoulder aches.
- Changes in mood – irritability, sadness.
- Tearfulness.
- Loss of interest in activities/hobbies.

Recognising these mental health difficulties and talking with friends and family or paid carers/support workers can often help to resolve them, particularly when steps are taken to promote mental well-being using the Five Ways or similar approaches.

Case study: supporting mental well-being – Joe's day service

Joe has a learning disability and attends his local day service three days a week. He has friends there and enjoys the activities, but mostly the company of others. The service is closing as part of a redesign and Joe is very worried about this as he does not yet have an alternative service. His care staff recognise that he is anxious as he paces around repeating 'closure' and cries. They know that he has experienced mental health

difficulties in the past and they want to minimise the risk of this happening to Joe again. Joe and his team talk about their concerns and decide to be proactive in minimising the disruption. Joe is supported to buy an address book and record the names and addresses of his friends and their carers so that they can keep in contact. They arrange a meeting all together to discuss the closure and agree that once a week they will meet to go bowling and have a meal at the local leisure centre. Joe remains worried about the closure but he has stopped pacing and crying because he can still be active, connect, and learn new things as part of the group initiative.

Role of the support worker/family carers

Support workers can be instrumental in helping a person with a learning disability to recognise and communicate their feelings and then work in partnership to find ways to improve mental well-being. When supporting someone with a mental health difficulty it is important to listen and give the person time and space to express themselves. Some people with a learning disability may not be able to verbally communicate their thoughts and feelings, and could instead show their distress through behaviour that challenges us. Non-judgemental, person-centred approaches that are tailored to the person's communication needs should form the basis of any care and support. Practical steps that may help to reduce distress could be:

- Show the person that they are valued.
- Give the person opportunities to make choices.
- Find relaxing activities i.e. music, adult colouring, walking.
- Temporarily provide relief from stressful situations i.e. a 'duvet day', skipping chores, having a lie in.
- Provide temporary extra support to increase participation in activities.
- Increase time with family or friends or keyworkers.

With support from friends and family these mental health difficulties are likely to resolve themselves, however for some people this will not be the case. The mental health difficulties may become more pronounced and overwhelming. They may impact on the person's ability to go about their daily lives. When this happens, then support should be sought from health services.

Getting help

Case study: Joe's deteriorating mental health

Joe's day service eventually closed and he still did not have an alternative service to go to. While he and his group of friends continued to meet, some had left the group and sometimes the group would be cancelled at short notice. He spent most of his time in the house by himself. Joe's staff team began to notice that he was becoming anxious again. Joe was pacing and crying and did not want to eat with the others and he was not sleeping well. The staff noticed that Joe had lost weight as his clothes were very baggy and he was becoming irritable, shouting and slamming doors. They supported Joe to see his GP who was concerned that he was showing signs of depression. The GP referred Joe to his mental health in learning disability team for assessment and treatment.

When a person's mental health difficulties affects their day-to-day life and ability to carry out their normal routines, then the first place to seek support is usually through the GP. GPs can assess mental health difficulties, make referrals to mental health services where appropriate or can treat mild mental health problems within the surgery e.g. prescribe medication or talking therapy. It is important to alert the GP that the person has a learning disability and may therefore require reasonable adjustments during the consultation (reasonable adjustments are a legal obligation to all public services to make physical and psycho-social adjustments to their services to allow equal access for people with disabilities). The GP will require information about the nature of the problem, how long it has been going on for, what changes have occurred and what the concerns are from the perspective of the person with a learning disability and from any staff or family carers who may be involved. It is helpful to take along any medications that the person may be taking as well as any communication aids or items that may help the person with the consultation.

Examples of mental health difficulties that require healthcare intervention include:

- Feelings of lethargy, lacking energy and motivation.
- Thoughts become negative and the person may feel their situation is helpless.
- Problems concentrating.
- Eating too much or too little, with changes to their weight/appearance.
- Sleeping too much or too little.

- Getting easily emotional or tense and experiencing mood swings. They may also be in a state where they are constantly worried, nervous or scared. This may cause conflict in everyday situations.
- Physical symptoms might include racing pulse, feeling sick, feeling that there is something physically wrong with them.
- Unpleasant thoughts that they can't stop thinking about and which cause them stress (ruminations).
- Hearing voices that are not there (hallucinations).
- Have false beliefs about everyday situations that are not true (delusions).
- Having thoughts of harming or hurting themselves or others.
- Experiencing irrational fear and panic.
- Experience other physical symptoms such as sweating, heart palpitations, breathlessness and pain.

(Adapted from Chaplin *et al*, 2016)

Sometimes, mental illnesses can develop very quickly. If a person appears to have lost touch with reality and is acting strangely or has active thoughts about harming themselves or others, then immediate mental health care should be sought. Accident and Emergency departments have mental health liaison teams who can assess and treat mental health difficulties 24 hours a day, seven days a week.

Assessment challenges

Assessing mental health difficulties in people with learning disabilities can be challenging. This is because the standard assessment process relies on the person being able to give a verbal account of their experiences, thoughts, feelings and timescales, as well as any potential distress. The intellectual and cognitive abilities to be able to do this are complex and involve memory, recall, thought processing, problem solving, understanding of time and being able to understand and respond to questions. For many people with a learning disability, some adjustments to standard interview techniques will help to overcome these difficulties. For example:

- a good use of open and closed questions
- 'anchoring' time to particular events, for example, 'Did you feel like this at Christmas?' rather than, 'How long have you felt like this?'
- asking the same question in different ways and at different times in the interview
- augmenting verbal communication with gestures, facial expressions or using objects, photos or symbols.

However, for those with more significant difficulties, health staff should also rely on family and carers to provide information about changes in appearance, behaviours and sleeping and eating habits, for example. You may be asked to keep a diary or monitoring charts or be asked to support an individual to monitor their own mood using visual scales.

Here is an example of a mood and coping diary:

Example 1

John felt upset so he looked at his SAINT book. Looking at the feelings list he saw number **6** – I feel down.

Number 6 is about sadness.



John put the number 6 in his diary and thought: 'I must look at the ideas for coping in the SAINT book to see if I can help myself'.

The coping list gave John ideas that could help him. He thought, 'I know, I will listen to music.' This was number **16** – listening to music or watching TV.

John put number 16 in his diary.

John also wrote a note in his diary that this made him happy.

WEEKLY DIARY	
Monday	Friday
6 I felt sad this morning and listening to music made me feel better	
Tuesday	Saturday
Wednesday	Sunday
Thursday	NOTES

(Chaplin, 2014)

A visual mood scale, happy or sad:



The information that these charts can provide form a significant part of the assessment process and should be completed accurately and consistently to provide the best evidence.

NICE guidance on the assessment of mental health difficulties in people with a learning disability also states that health staff should be aware:

- *‘that an underlying physical health condition may be causing the problem*
- *that a physical health condition, sensory or cognitive impairment may mask an underlying mental health problem*
- *that mental health problems can present differently in people with more severe learning disabilities’*

(NICE, 2016)

The assessment process should therefore be holistic and take account of current physical health and avoid ‘diagnostic overshadowing’, where difficulties are attributed to the person’s learning disability rather than an underlying mental and/or physical illness. Common physical health conditions that can manifest as mental health difficulties are urinary tract infections, an under- or overactive thyroid as well as experiencing pain. Annual health checks and proactive responses to changes in an individual’s presentation are key to detecting and treating health conditions in a timely way, and people with a learning disability, carers and family members should proactively seek these out⁴.

For some people with more severe disabilities, some signs and symptoms of mental difficulties can present differently. For example:

- skin picking
- hair pulling
- face slapping
- psychogenic vomiting (where the person vomits without any physical cause and it is not self-induced).

These behaviours should be carefully assessed taking account of biological factors such as sleeping and eating habits, appearance and demeanour, and significant life events that may have occurred. A functional analysis and psychiatric assessment could also be undertaken to establish the origin of the behaviours.

It is vital that carers/family members should make sure that they and the person they are supporting are prepared for the appointment. They should ensure that health staff are aware of the learning disability and help them to make reasonable adjustments. They should bring communication aids or items that will help with interaction and communication between the person with a learning disability and the health professional. They may wish to use more

⁴ For more information, see Mencap’s *Don’t miss out!* available at: <https://www.mencap.org.uk/advice-and-support/health/dont-miss-out> (accessed December 2017).

formal items such as hospital passports or informal everyday objects of interest to the person with a learning disability that could aid interactions and reduce any worries/anxiety. Support workers and family carers should also be aware that after the assessment or consultation, the person that they are supporting might need extra support because they have had to speak about distressing and upsetting symptoms or events with health staff. Plan extra time to be with the person afterwards to provide support and assurance. It may be helpful to take note of things that have worked well and things that have not worked quite so well, which can then be used to plan for and support someone through future appointments.

Specific conditions

There are many types of mental illness and disorder. The table below looks at four common mental health conditions – generalised anxiety disorder, bipolar affective disorder, depression and schizophrenia – and how they may present differently in people with learning disability. The estimated rates of mental illness among people with learning disabilities for these conditions are:

- Generalised anxiety disorder: 6%
- Bipolar affective disorder: 1.5%
- Depression: 4%
- Schizophrenia 3%

Mental health problem	Common symptoms	Treatment
<p>Generalised anxiety disorder</p>	<p>The person may be unable to concentrate e.g. follow a conversation or do basic tasks they would normally do with ease.</p> <p>The person may develop irrational fears of everyday situations or doing things that posed no problem before (panic).</p> <p>The person may avoid social occasions because being</p>	<p>The treatments commonly used for anxiety are talking therapies, self-help and self-management, which includes:</p> <ul style="list-style-type: none"> • counselling • CBT • guided self-help • self-help resources <p>Probably the most commonly prescribed treatment for anxiety is talking therapies based on</p>

Mental health problem	Common symptoms	Treatment
<p>Generalised anxiety disorder (cont.)</p>	<p>with people makes them feel anxious (social anxiety).</p> <p>The person may get physical signs and symptoms such as sweating, pulse racing, stomach upset. The person will become distressed, for example they may be convinced that they are having a heart attack.</p>	<p>cognitive behavioural therapy (CBT). This may include self-help resources either as part of treatment or sometimes as a resource that the person can use independently or with support to manage their condition.</p> <p>Other treatments include relaxation therapy and breathing exercises to help the person to remain calm and relax. For people with learning disabilities this can also involve learning about their symptoms as part of a self-management programme.</p> <p>For those with phobias, treatment will focus on desensitising the person to the object they hold an irrational fear of. In episodes of severe and acute anxiety, sometimes medications will be prescribed for a short period.</p>
<p>Bi-polar affective disorder</p>	<p>The person may have mood swings from being depressed (see above) to being excitable and overactive (hypomania). Some people with bipolar may have mainly depressive episodes.</p> <p>When hypomanic, the person will have reduced sleep or not sleep at all. The person may become disinhibited or promiscuous, or their behaviour may become, extreme, reckless or chaotic.</p>	<p>A number of different treatments are used to treat bi-polar disorder. Often mood stabilising medication is used to prevent symptoms of mania, hypomania and depression. When symptoms are acute, anti-depressants can be used to treat the depression and anti-psychotic medication to treat mania or hypomania. Psychological treatments are often used to target depression and often to make sense of</p>

Mental health problem	Common symptoms	Treatment
<p>Bi-polar affective disorder (cont.)</p>	<p>For example they may take drugs or spend money they do not have. The person may feel or act in a grandiose manner and have feelings of self-importance, or take on jobs and tasks they are not capable of or are unable to complete.</p>	<p>behaviour when unwell and to stay mentally well.</p> <p>For some people, hospital treatment may be necessary if there's a danger the person might hurt themselves and/or others.</p>
<p>Depression</p>	<p>When depressed, a person may:</p> <ul style="list-style-type: none"> ■ have reduced appetite ■ have difficulty sleeping ■ be unable to concentrate on normal tasks ■ be lethargic and lack energy or motivation ■ stop doing things they would normally enjoy. 	<p>Treatment for depression depends upon how severe it is e.g. mild depression might improve by itself or through self-management such as exercise or positive thinking.</p> <p>For mild to moderate depression treatment is more likely to be a talking therapy, such as counselling or cognitive behavioural therapy (CBT).</p> <p>For moderate to severe depression, meanwhile, in addition to these treatments, antidepressants might be prescribed, known as combination therapy.</p> <p>For severe depression, you may be referred to specialist mental health services and, as well as the treatments mentioned earlier, you might be prescribed electroconvulsive therapy where there is risk to the person.</p>

Mental health problem	Common symptoms	Treatment
Schizophrenia	<p>Presentation of schizophrenia is split into negative and positive symptoms.</p> <p>Negative symptoms are likely to appear as chronic symptoms, including:</p> <ul style="list-style-type: none"> ■ apathy ■ social withdrawal ■ lack of interest in surroundings. <p>Positive symptoms often occur in acute phases where the person may have delusional beliefs, which are false beliefs that are not grounded in experience and that other people do not share and that are unshakeable.</p> <p>They may have hallucinations such as hearing voices that are not there.</p> <p>They may be paranoid or have feelings of being persecuted. The person may have thought disorder – for example, someone is controlling their thoughts or putting in or taking thoughts out of their head.</p>	<p>Antipsychotic medication is usually recommended for the treatment of schizophrenia.</p> <p>Antipsychotics can reduce feelings of anxiety or aggression and other symptoms, such as hallucinations or delusions.</p> <p>Antipsychotics can be taken orally, given as a depot injection, which releases medication over time so the person would have an injection every two to four weeks.</p> <p>Side effects will differ depending on what type of anti-psychotic is used – older typical antipsychotics are characterised by Parkinson type side-effects including shaking, muscle spasms and abnormalities of gait whereas with atypical antipsychotics the side effects will include weight gain.</p> <p>All may cause:</p> <ul style="list-style-type: none"> ■ drowsiness ■ blurred vision ■ constipation ■ loss of libido ■ dry mouth. <p>Medications should be regularly reviewed.</p> <p>Psychological treatments are also used to lessen the impact of symptoms such as hallucinations or delusions.</p>

Mental health problem	Common symptoms	Treatment
Schizophrenia (cont.)		Psychological treatments are also used to lessen the impact of symptoms such as hallucinations or delusions. They can also improve other negative symptoms, such as lack of motivation and apathy.

Recovery

Care and treatment in the above examples should be delivered within the recovery framework. Recovery is a person-centred concept used in mental health services to describe the processes that someone goes through to either overcome or live with their mental health difficulties in a positive way. That is to say, a process of recovering one's ability to live a fulfilling life, cope with everyday stressors and have hope for and control over one's life. After a period of mental ill-health, it is important that a person with a learning disability is also supported with their path to recovery. Local mental health services can provide support to develop meaningful plans in collaboration with people with a learning disability and their family or carers. Although there is little written about recovery specifically for people with a learning disability, the principles are similar to person-centred planning, so in terms of mental health we need to take into account the signs of poor mental health and triggers to assist early recognition of mental illness and health problems to allow access to early intervention. For successful recovery, it is important that the person with mental health problems takes the lead with support as far as possible in managing their condition.

Key learning points

- Mental health and well-being affects us all.
- It is important to promote and maintain our mental health.
- People with a learning disability may need support to engage in activities that will promote their mental well-being including using the 'Five Ways' to mental well-being approach.

- Mental health and well-being is an important element of care and support as people with a learning disability are more likely to experience mental illness than the wider population.
- Mental health assessments can be a challenge to undertake in some people with a learning disability.
- People with a learning disability are at increased risk of hospital admission and overuse of psychotropic medication if they experience mental health difficulties.
- Support staff and family carers need to be prepared for appointments and ask for reasonable adjustments to be made.

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Useful websites and resources

Mental Health Nursing of adults with learning disability https://www2.rcn.org.uk/__data/assets/pdf_file/0006/78765/003184.pdf

Foundation for people with learning disabilities
<https://www.mentalhealth.org.uk/learning-disabilities/about-us>

Mencap

<https://www.mencap.org.uk>

Royal College of Psychiatrists

<http://www.rcpsych.ac.uk/healthadvice/problemsdisorders/learningdisabilities.aspx>