



## **Adults with a learning disability and mental health problems**

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***This factsheet looks at adults who have a learning disability and also have mental health problems.***

*What is a mental health problem?  
What causes mental health problems?  
What treatments are there for mental health problems?  
How does the mental health system work?  
Problems with accessing appropriate treatment  
What can I do if my son or daughter is not being offered appropriate treatment?  
What can I do if I have concerns about psychiatric medication my son or daughter is prescribed?  
What can I do if I am unhappy that my son or daughter is in a psychiatric hospital?*

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### ***What is a mental health problem?***

People with a learning disability can experience mental health problems, just like people without a learning disability. Mental health problems can include schizophrenia, bipolar affective disorder (also known as “manic depression”), anorexia and bulimia, phobias and depression, to name just a few. The Royal College of Psychiatrists' website has information which describes the different types of mental health problems and also includes information on specific mental health problems in people with a learning disability, such as, depression in people with a learning disability.

### ***What causes mental health problems?***

There are many different theories, and much

disagreement, about what causes mental health problems. Possible causes of mental health problems in people with a learning disability may include:

- genetics
- damage to the brain that has caused the learning disability
- traumatic events in childhood, for example abuse
- traumatic events in adulthood
- misuse of alcohol or illicit substances
- not having enough control over their own lives
- not having enough stimulating things to do in their own lives
- social isolation
- bullying and discrimination
- difficulty expressing emotions, or not having anyone to express them to.

One theory is that a person's mental health problem may have more than one cause; two factors may interact with each other to cause a mental health problem. For example, if someone has a genetic tendency towards mental health problems, they may not develop them unless they experience a traumatic event.

### ***What treatments are there for mental health problems?***

There are different theories about what treatments are helpful for mental health problems. Most research in this area does not include people with a learning disability. However, there is a growing body of research supporting the effectiveness of some treatments for people with a learning disability. Some are more useful for some types of mental health problems than others. Also, people respond differently to treatments (or interventions); what helps one person might not help another. These treatments are not mutually exclusive and one person may benefit from a combination of interventions:

- Counselling, psychotherapy and other talking treatments
- Medication
- Alternative and complementary therapies, for example yoga, aromatherapy, homeopathic remedies.
- Making changes in someone's life, for example

making sure the person has enough to do,  
helping the person have more control over their  
life.

- Dealing with discrimination and bullying.

## ***How does the mental health system work?***

### ***The Care Programme Approach (CPA)***

The aim of this system is that all users of mental health services should have care within a framework offering:

- arrangements for assessing the health and social care needs of people using mental health services
- a ***care plan*** clearly identifying health and social care required from a variety of providers
- a care co-ordinator (keyworker) to co-ordinate
- regular reviews and agreed care plan changes.

For this to work properly with people with a learning disability, it is vital there is joint working across health, social services, mental health and learning disability services.

In 2001, the Government published a ***White Paper*** called "Valuing People: A New Strategy for Learning Disability for the 21st Century" in England. It is the Government's strategy for addressing all key issues relating to people with a learning disability. Within this White Paper it is proposed that by 2005 everyone with a learning disability will be offered a "***Health Action Plan***" which will detail the actions needed to maintain and improve people's health. These should include mental health and can be incorporated into the care plan using the Care Programme Approach. In Wales "Fulfilling the Promises" was published. In Northern Ireland "Investing in Health" with related strategies was developed.

There has recently been new guidance (2008) from the Department of Health called "Refocusing the Care Programme Approach".

### ***Hospitals***

Some psychiatric hospitals have beds allocated specifically to people with a learning disability but there aren't many. Sometimes there are Registered Learning Disability Nurses (RNLDs), working on the

wards, but there are not enough of them. Registered Learning Disability Nurses are not necessarily trained in mental health.

There are a few psychiatric hospital wards in existence specifically for people with a learning disability who are experiencing mental health problems.

In many parts of the country there are no psychiatric wards or beds that are specifically for people with a learning disability who are experiencing mental health problems. Staff running mainstream psychiatric hospital wards are often unable or unwilling to provide a service to people with a learning disability.

### ***Problems with accessing appropriate treatment***

You may have difficulty getting an assessment of your son or daughter's mental health needs or find that the only treatment offered is medication and/or hospital admission. This can be because it has traditionally been believed that some of the things experienced by people with a learning disability that could be viewed as mental health problems are just automatically part of the person's learning disability, when in fact there are often additional causes that can be addressed. It has also been thought traditionally that people with a learning disability are not able to benefit from some mental health treatments, such as talking treatments. All these assumptions have been challenged in recent years.

Another problem is the lack of counsellors and self-help groups experienced in working with people with a learning disability.

### ***What can I do if my son or daughter is not being offered appropriate treatment?***

- Suggest that the cause of the mental health problem is looked at
- Suggest that a particular treatment is offered

Neither of these means that these things will happen, but it does mean that the professionals will need to discuss with you their reasons for not doing this.

## ***Advocacy***

An advocate is someone who helps to speak up on behalf of a person with a learning disability or a mental health problem for the services that person wants. Unfortunately, many advocates that work with people with mental health problems don't have experience with people with a learning disability and many advocates that work with people with a learning disability don't have experience of working with mental health issues or the mental health system. Nevertheless, an advocate may still be able to help. In some parts of the country, there may be advocates who are experienced in both areas.

## ***Valuing People White Paper***

"Valuing People" is the Government's ***White Paper*** on learning disability and sets out what should be happening. There is a section on health of people with a learning disability. It says that people with a learning disability should have equal access to mainstream NHS services, and has a specific section on equal access to mainstream mental health services. So if your local NHS Trust and Primary Care Trust provides mental health services such as talking treatments (e.g. counselling, psychotherapy) to other people but not to people with a learning disability, they are not acting in line with Government policy. In Wales "Fulfilling the Promises" was published.

## ***Complaints about the NHS***

NHS Trusts and Primary Care Trusts have a Patient Advice and Liaison Service (PALS) that replaced the Community Health Council (CHC). If your son or daughter is having trouble getting an NHS service e.g. counselling, and there isn't a good reason for this, PALS can help liaise with them or help make a complaint. If PALS can't resolve the situation, you could then use Independent Complaints and Advocacy Services (ICAS). (This is not the same as the advocacy services described above.) In Northern Ireland PALS is not available. The Health and Social Services Councils still operate in the four Health and Social Services Boards.

## ***Disability Discrimination Act***

The Disability Discrimination Act says that providers

of services cannot treat a person with a disability less favourably because of a reason related to their disability, unless it is justified. Services include services provided by the NHS, as well as private and voluntary practitioners, counsellors and therapists. The NHS can treat a person with a disability less favourably if there is a medical reason for it. So if your local NHS Trust provides counselling for example, but says, "We don't give it to people with a learning disability", they are likely to be breaching the Disability Discrimination Act. If however, the therapist/practitioner gives an individual with a learning disability a proper assessment and decides that it is their genuine clinical judgement that a particular person would not be able to benefit from counselling, then that would likely to be considered a medical judgement and not against the Disability Discrimination Act.

### ***Meeting with the care home***

If you feel your son or daughter's mental health problem is being caused or made worse by a social problem e.g. not enough to do, not being treated with respect, not being encouraged by staff to make their own choices, it may help to have a meeting with the care home.

### ***Community care review/meeting with the social services***

If you feel that your son or daughter's mental health problem is caused by a social problem as explained above, you can ask for a meeting with your son or daughter's **care manager** from the social services, even if the care home is a private home. This is because social services still have a responsibility to make sure the original **care plan** is still going well, and to carry out regular reviews.

### ***Complaints about social services***

If your son or daughter's mental health problem is being caused by, or made worse by, problems with services arranged by social services as explained above, then you can make a complaint using the social services complaints procedure. You can make a complaint to social services even if the care home is a private or voluntary organisation's home.

## ***What can I do if I have concerns about psychiatric medication my son or daughter is prescribed?***

***(This section relates to adults with a learning disability only, not children).***

You may feel that your son or daughter should not be on psychiatric medication, or that s/he is on the wrong medication, or that the dose is too high, or you may be concerned about side effects.

- Being on more than one psychiatric drug at a time generally increases the risk of side effects.
- People with brain damage are often more sensitive to the effects of medication than other people.
- PLEASE NOTE: SOMEONE SHOULD NEVER COME OFF PSYCHIATRIC MEDICATION WITHOUT MEDICAL SUPERVISION. WITHDRAWAL EFFECTS ARE OFTEN WORSE THAN THE SIDE EFFECTS OF TAKING THE MEDICATION, IF WITHDRAWAL IS NOT DONE PROPERLY AND GRADUALLY.
- For information on all of these medication issues, you could talk to your local pharmacist.
- If your son or daughter has the mental capacity to give informed consent, or informed refusal to consent to medication, then currently, medication cannot lawfully be given without that person's consent unless they are detained in hospital under the Mental Health Act. A new amended Mental Health Act (2007) will come into effect on 3rd November 2008.
- The Elfrida Society has information about psychiatric medication that is written and illustrated in an easy-to-understand way for people with a learning disability.
- If your son or daughter does not have the mental capacity to give informed consent, then a doctor can prescribe medication if they believe it is in the person's best interests.
- An advocate may be able to help – see earlier section on advocacy.

## ***What can I do if I am unhappy that my son or daughter is in a psychiatric hospital?***

***(This section relates to adults with a learning disability only, not children)***

If your son or daughter has the mental capacity to consent to going into a psychiatric hospital, or to

refuse to consent, then if a professional thinks they need to be in hospital they must follow the law about detention under the Mental Health Act. This means that they can put the person into hospital against their will, but only if certain criteria are met and the right procedures are followed.

If your son or daughter does not have the mental capacity to consent to going into a psychiatric hospital, then currently the law is unclear about keeping him/her in a psychiatric hospital. The Government has written some advice for hospitals about what to do until the law is changed and made clear. However, there is a proposed addendum to the Mental Capacity Act 2005 which looks at the 'Deprivation of Liberty' safeguards. The advice suggests that if professionals are considering keeping a person with a learning disability in a psychiatric hospital and the person does not have the mental capacity to consent or refuse consent, then staff should:

- Make sure that decisions about hospital admission are taken in a structured way with proper safeguards
  - Make sure there is care planning recorded in writing, with appropriate involvement of the family and with reviews.
  - Make sure that alternatives to hospital admission are considered and that any restrictions placed on the person whilst in hospital are kept to the minimum necessary.
  - Make sure that appropriate information is given to the family, including information about the purpose and reasons for admitting the person to hospital.
  - An advocate may be able to help - see the section on advocacy.
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### **Key terms:**

- 1. Health Action Plan** - a plan detailing what actions are needed to maintain a persons health
- 2. Care Plan** - a list of the support a person with a learning disability will get. It says who will give support, what time they will give support, and how long they will give support for.
- 3. White Paper** - a report giving details of how

changes are being made by the Government  
**4. Care Manager** - the person who writes a care plan,  
and puts together and manages services for a person  
with a learning disability.

***This document was approved by Dr Jane McCarthy on 31/10/2008***