



Treat me right!

Better healthcare for people with
a learning disability

MENCAP
Understanding learning disability

Accessible
Summary

Contents

1	Introduction	3
2.	People with a learning disability and their experiences of health services	6
3.	What Mencap wants	11
4.	More information	15

Please note that, in the case studies in this report, the names of the people involved have been changed to protect their identity. The photos are for illustrative purposes only and use models.



1. Introduction



Many people with a learning disability have poorer health than other people. A big reason for this is that people with a learning disability get poorer health services than other people. In the worst cases, this leads to people with a learning disability dying.

Max's story

Max was 30 when he broke his hip. He was in hospital for several weeks. During this time Max was having fits, moaning and punching himself in the face because he was in a lot of pain. Nobody at the hospital listened to Max's parents and he was sent home from hospital twice.

Eventually the doctors found out that Max had blood poisoning because his kidneys were not working properly. Max died.

If Max had been looked after properly and doctors had noticed his kidney problems, his parents believe he would still be alive.



Mencap thinks many people with a learning disability would have better health if they got better health services.



This report called ***Treat me right!*** looks at:

- the reasons many people with a learning disability have poorer health than other people
- people with a learning disability and their experiences of health services
- the changes Mencap wants to happen.



Through ***Treat me right!*** Mencap is asking health services and health staff to make big changes to health services for people with a learning disability.



Outpatient

5

Dental Tests

4

ENT

4A - Medical Clinics
4B - Oral Surgery
4B - Audiology
4B - ENT

4B

Eye Clinic

Speech

4C

Women's

3

This Level

Clinics

3B - Medical Clinics
Podiatry

Medical Clinics

Cardiac Invas

ECG & EEG

Appointments

Green Zone

Pharmacy (overseas)

40 - Children's

Orange Zone

2

Accident & Emergency

CT Scanner
MRI Scanner
X-ray

Main Reception

2 0 5 1 1

Way Out & B

1

ENT

1A - Medical Clinics
1B - Fracture Clinic
CAMDOC
R&G Physiotherapy

GP X-ray

Narcosis Med

Pharmacy

Ultrasound



Why do many people with a learning disability have poorer health than other people?

We know that many people with a learning disability have poorer health than other people and are likely to die younger. Some reasons for this are:



- people with a learning disability are more likely than other people to die because of things like chest problems and heart disease



- many people with a learning disability have more health problems than other people, like epilepsy (having fits) and thyroid problems (which leads to putting on weight).



- things like being poor, not having a job or not being able to do the things you enjoy can make you less healthy – these things affect many people with a learning disability



- eating bad food and not exercising make you unhealthy. Many people with a learning disability live in residential homes or with their families – this can mean they do not get to choose the food they eat, and it is harder for them to do exercise.

But there is another reason why people with a learning disability have poorer health than other people – **they do not get the health services they need.**



Having a learning disability does not mean that you should have poorer health than other people. Health services should not use the above reasons as an excuse not to give people with a learning disability the health services they need.



Mencap thinks many people with a learning disability would have better health if they got better health services



2. People with a learning disability and their experiences of health services



Mencap asked 1,000 people with a learning disability about their experiences of using health services. Many people were happy with their health service. But other people had some terrible experiences.

This section looks at some of the problems people with a learning disability face when using health services, and what needs to change.

a) Who cares for people with a learning disability?

Sarah's story

“I was shocked when the surgery didn't seem prepared to treat Sarah and referred her back to the learning disability team.”

Mandy, Sarah's mother



Some health services do not think it is their job to treat people with a learning disability – they think people with a learning disability should be treated through separate learning disability services.

People with a learning disability should get the help they need from health services just like everybody else.

b) Going to the GP (doctor) or clinic

Ibrahim's story

“My GP is always in a rush. I feel rushed because I don't have enough time to explain what's wrong and I don't always understand what he says to me.”

Ibrahim



Many GPs find it harder to treat people with a learning disability because they do not understand their needs.

GPs should give people with a learning disability more time to explain what is wrong and should listen to them carefully. They should check that people with a learning disability have understood what they have been told.

c) Understanding learning disability

Simon's story

Simon was distressed and his parents knew he was in pain. They took him to see the GP. But the GP did not listen to Simon's parents. He told them: "That's just the way they are sometimes. Just take him home".

Luckily Simon's dentist found the problem. Simon's mother says: "I hate to think how much pain he must have been in."



Some GPs think that the health problems people with a learning disability have are a result of their disability. So they do not take health problems in people with a learning disability as seriously as in someone without a learning disability.

GPs and other health staff should not assume that because someone has a learning disability, not much can be done to help them.



d) Training and skills

Cathy's story:

“Cathy has been wearing a hearing aid ever since she went for a hearing test. There was nothing wrong with her before she went”.

Lorraine, Cathy's carer

Cathy has Down's syndrome. But the doctor did not know that the inside of her ear was different to other people's because she has Down's syndrome. He pushed an instrument too far into her ear and damaged her hearing.



Health staff should know about the different health needs of people with a learning disability. They also need to know how to communicate with people with a learning disability. There should be accessible information available for people with a learning disability.

e) Poor health care

Anthony's story

“We had to stay with Anthony from 10am to 10pm because no one was feeding him”.

Diane, Anthony's mum

Health staff in hospitals do not always understand or try to meet the needs of people with a learning disability.



Health staff should not rely on parents to look after their sons and daughters when they stay in hospital.

f) Discrimination

Victoria's story:

"I overheard the doctor say: 'that's not coming in my room. It will destroy the equipment'."

Jean, Victoria's mum



Sometimes people with a learning disability might be discriminated against (treated badly) by health staff because they have a learning disability. This must not happen.

g) Not saving people's lives

Victoria's story:

"Victoria was rushed to hospital after a series of seizures. She needed to be put on a ventilator. The doctor came up and spoke to us. He was suggesting that it wasn't worth trying to save her".

Jean, Victoria's mum



There is evidence to suggest that (some people think that) doctors have sometimes decided not to save the lives of people with profound and multiple learning disabilities because they think it would be better for them to die.

Doctors should never decide not to save people's lives just because they have profound and multiple learning disabilities.



3. What Mencap wants



Treat me right! shows that many people with a learning disability do not get the health services they need. Because of this, they have poorer health, more health needs and die younger.



The Government and health services have shown that they want to make health services better for people with a learning disability – they have produced good policy and practice guidance. But people with a learning disability are still getting a poor deal.



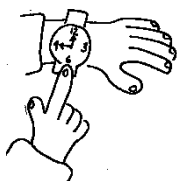
Mencap thinks there are some important things that must happen to make sure that people with a learning disability get good health services:



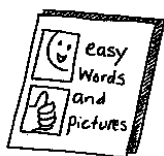
- **Health staff should have learning disability training.**

Many of the terrible experiences in this report happened because staff did not know enough about learning disability.

- **Health services should make sure they give people with a learning disability the services they need.**



The Disability Discrimination Act says that health services have to give people with a learning disability the services they need. To make sure this happens, health services should:



- **give people with a learning disability longer appointments**
- **provide accessible information for people with a learning disability**



- **make sure people's records show that they have a learning disability** (this would help doctors and nurses to be aware of and meet people's needs).



- **Doctors should look out for health problems in people with a learning disability.**



Doctors should do more to look out for health problems in people with a learning disability so they can give them the right treatment. They should do this by:

- **giving people with a learning disability a health check every year if they want one**



- **making sure that people with a learning disability are invited to go for special tests to check for things like cancer, like everybody else.**

- **Health services must do all they can to stop people with a learning disability having poorer health than other people.**



The Government is trying to make sure that different groups of people, such as people with a learning disability, do not have poorer health than other groups of people. This is called the 'Health Inequalities Agenda'. As part of this work, health services should make sure that:

- **people with a learning disability get the treatment they need from health services, like everybody else**



- **they do all they can to stop people with a learning disability dying younger than other people.**





- **Health staff must give people with a learning disability the support they need when they are in hospital.**



Hospitals have to give people the support they need when they are in hospital. This is called a ‘duty of care’. Hospitals should not expect parents or carers to provide support that should be given by healthcare staff.

- **There must be an inquiry into why people with a learning disability often die younger than other people.**



Through an inquiry, the Government would try to find out why people with a learning disability die younger than other people. If we knew the reasons for this, it would help to improve health services for people with a learning disability and help them to live longer.

4. More information



To read the full report and to get information on healthy living and good practice, see the Mencap website:

www.mencap.org.uk/treatmeright



If you need help and advice on anything to do with learning disability, call the Learning Disability Helpline free on: **0808 808 1111**



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To ask for this document in a different format, contact the Helpline numbers above.

You can also get this document from the Mencap website at **www.mencap.org.uk**