

A life like no other

A national audit of specialist inpatient healthcare services for people with learning difficulties in England

Easy read summary



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and Inspection

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About this easy read summary



This is a short report that tells you the most important things from the bigger report.

You can get copies of the bigger report by telephoning the Healthcare Commission's helpline on 0845 601 3012 or looking on our website www.healthcarecommission.org.uk

There is also a DVD, which tells you about people's experiences of doing the audit. It also shows some better practice in services. You can also get copies of this by telephoning the number above.

About the Healthcare Commission



The Healthcare Commission is independent. We are not part of the NHS.

Our job is to:

- support health services to do a better job
- help people living in England to be healthier



The law says that the Healthcare Commission has to:

- check that health services in the NHS are doing a good job
- tell services how well they are doing
- organise inspections and reviews of health services that are not part of the NHS
- register health services that are not part of the NHS

We decided to do this audit because we had already found problems in some NHS services for people with learning difficulties. We found out that some people with learning difficulties were being abused where they lived, and treated very badly because of how services were organised. We have also been worried about independent health services that are not run by the NHS.

We have used the words “learning difficulty” instead of “learning disability” in this report because people with learning difficulties asked us to.



About this audit



The Healthcare Commission agreed to do an audit in 2007 to check on health services in England that are especially for people with learning difficulties. We looked at the services that are run by the NHS, or paid for by the NHS.

- we looked at specialist services for adults and young people with learning difficulties
- we did not look at the health services that everyone uses for instance GP services or acute hospital services
- we did not look at services run by social services or paid for by social services

We wanted the audit to:

- find out how many special health services there were for people with learning difficulties in England
- find out what these services were like
- collect information that would help us work out what needs to be checked regularly when looking at health services



We want the audit to make a difference:

- by getting services and others to take action now and plan for the future
- by making sure that all these services are as safe as possible for people with learning difficulties
- by sharing this report with as many people as possible
- by getting people to talk about the problems in services for people with learning difficulties and think about ways to make them better

We did this audit to make sure that people's human rights are respected.

About people with learning difficulties and the services they get

Sometimes people need support and care. We must help people to be as independent as they can be and achieve what they want to. We must make sure that people have the right care, in the right place, at the right time.

Most people with learning difficulties who need support get help from social services or other organisations that help people to live as part of their community.

Most people with learning difficulties live with their families, some people live in their own home and some people live in care homes that are checked by the CSCI.



CSCI stands for the Commission for Social Care Inspection.



We found out that there are 638 learning difficulty services that this audit needed to look at. These services are in 72 NHS trusts, and 17 health services that are not part of the NHS but are registered with the Healthcare Commission. We did not have this information before doing the audit.

There are about 4,000 people with learning difficulties getting help from these services. Most of the people were between 25 and 55 years old. Most were white, British, men. There were women and people of different ages and different ethnic backgrounds, but not as many.

There is not a clear system for checking all these services. Other services are checked by national health targets or a national service framework, but services in health for people with learning difficulties do not have these.

How we did the audit

Attitudes to people with learning difficulties and the services they use have changed a lot. People are at last starting to be accepted. We included people with learning difficulties from the start as part of our planning group and our review teams. It was very important to us that we included people with learning difficulties, their families and other experts in this audit.

We wanted to help services to change as we went along so we:

- asked those running and working in services to take time out to look at how they were doing
- showed people other services that they would not usually get to see
- visited services
- trained everyone together including people with learning difficulties, families and other experts

How we did the audit continued



We got all the special health services that provide services for people with learning difficulties to write down the answers to lots of questions.

Then we visited some of them. We needed to see what it was really like for people with learning difficulties to be there. We visited 154 services that care for adults and young people. The team that did the visits usually included a person with a learning difficulty or family carer.



Every service we visited got a report saying what we thought about it and what things needed to be changed.

Our bigger report says a lot about what we found out. We want everyone to use this information and take action to make things better.

What we found out when checking these services

We found serious problems in six services. We took action to make things better.

We found a small number of services where some of the care that they gave people was good. But we found that most services were only giving basic care to people. Staff were trying to do a good job, but were not always supported by their organisation.

It is not good enough that some services or organisations are doing well, some are doing ok and some are doing badly. Even the better services were still not nearly as good as we expected them to be. Everybody should be able to get good care wherever they live.

What we found out when checking these services continued



The main things we found out

Many services were helping people to take part in different activities but others weren't. This was a problem even where people were living in locked places because the law said that they had to. These people should still be able to do different activities.

Services were not doing enough to make sure that people are always safe. We cannot be sure that the human rights of people with learning difficulties are always respected.

It was good that staff tried not to use force when people were so angry or upset that they could have hurt themselves or others. But most services were using 'PRN' or extra medication to calm people down or help them with their behaviour. We believe that there is not enough proof that using extra medication helps people with learning difficulties with their behaviour.

The main things we found out continued



There was not enough checking of services by those who run them, or by people outside of the service.

Commissioners, the professionals who agree and pay for services on behalf of people, were not doing enough to check up on services. Often health and social services were working together to buy services, but they did not seem to be checking the services they were paying for.

Advocates, families and other people from outside services can tell services where the problems are. We were concerned that many services were not helping people to get good advocates.

The main things we found out continued



Planning people's care was a problem. Many people with learning difficulties did not understand their care plans. The plans were not kept up-to-date or reviewed often enough.



The main things we found out continued

Often staff did not have basic training



Many services were old fashioned and were like institutions:

- people did not get help with planning their care
- people did not get to choose who they lived with
- people did not get to choose where they lived
- people were not living in decent places
- staff were not properly trained
- there were not enough staff working for the service, temporary staff were being used too often

We did not see enough good leadership in services. We cannot see how boards, management committees and service managers can be sure that the service they are responsible for is doing a good job.



We also found that the NHS and some other health services are still running homes for people with learning difficulties. People should be living in the community when they can. There are plans to close NHS campuses by 2010 and move people into new services. We are still worried about the other health services where this is still happening.

The main things we found out continued

From this audit we now know that there are some special health services that are mostly doing a good job for people



with learning difficulties. Staff are trying to do their best for people even though it can be hard.

But in most services we found that not enough is being done to make sure that people are getting a decent service or being kept safe. This is not good enough. There have already been many other reports that have said this. We all need to do something about these problems now!

What needs to happen

The way special health services are organised, paid for and run needs to change so that people are safe and get a decent service. These changes need to happen straight away.

People and organisations must now make a big effort to work together and use their power to make changes that will last a long time.

What the Healthcare Commission will do

We will check to make sure that services have made the changes they agreed to as part of this audit. We have asked that boards or management committees also check up on these actions.

We will start to do surprise visits to some of these services. This is to make sure that they have taken notice of this report, taken action and are respecting people's human rights.

We will use this information to check that what NHS trusts have told us about their services is true. For example when we check how well trusts meet standards for 2007/2008.

For 2008/2009 we want to use a new list when checking services. The things we want to look at will hopefully be scored as part of our check up of health services. We will say more about this in the next year. We will check:

- planning for care with people
- that NHS campuses close and people get services somewhere else
- how services keep adults and children safe
- issues around mental health

We will work with others to tell people about this audit.

We will work with the Commission for Social Care Inspection (CSCI) and the Mental Health Act Commission in 2008/2009 to check up on how trusts agree on and buy services (called commissioning) on behalf of people with learning difficulties.

What we expect others to do

We expect **all** special health services for people with learning difficulties to check their services and learn from this report. We have been told by independent people that the way we did this audit means that services have already started to change. We want services to keep looking at how they can be better.

We especially want **all** services covered by this audit to think about whether they should be providing the services that they do. We expect that some will decide that they are not the best organisations to be running long-term homes for people and other organisations should do this instead.





Even though some services might be worried about their money, we will be very concerned if because of this audit they suddenly decide to stop providing homes for people without first agreeing this with commissioners and learning disability partnership boards.

The Government has already said that NHS campuses need to close. We want each strategic health authority to look at how money and services are organised in their area. When they make changes it must be done in a way that involves people in planning, supports them to understand what is happening and respects their human rights.

Commissioners should use their power to make sure that people have a choice of services and that these services are safe, respect people's human rights, are well run and give good value for money.



What we expect others to do continued

Primary care trusts, their strategic health authorities and social services need to work together when agreeing, buying and checking services for people with learning difficulties.

During this audit, people with learning difficulties, their families, staff and managers and others said that there needs to be a national service framework, set by the Government for services for people with learning difficulties. They believe other kinds of services that have a framework have got better. The Healthcare Commission calls on the Department of Health to look at the problems and risks in these services when they decide on the rules for organisations that want to register with them in the future.

Staff are not getting access to the right training. We will look at this problem with others like strategic health authorities, the Department of Health, Skills for Health and universities.

By doing this audit we have been able to see what services are really like for people. We have developed questionnaires, training packages and a DVD. We have also trained lots of people who have helped to check services. We want learning disability partnership boards to make use of what we have done, and the people we have trained and start checking services.



We also want partnership boards to work with commissioners to decide what kind of health services should be in their area in the future.

We need to thank all the people with learning difficulties that were at the centre of this work.

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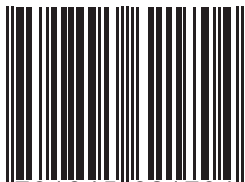
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