Commission for Social Care Inspection
CSCI
Making Social Care Better for People

Mental Health Act Commission

Healthcare Commission

Joint review of planning and buying services and support for people with learning disabilities and complex needs

Easy read summary

March 2009

Photography: S Hancock

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Commission for Social Care Inspection (CSCI)

It is our job to check adult social care services in England and to help make them better for people who use them.

Healthcare Commission (HC)

It is our job to make people's health and healthcare better in England.

We check health services like the NHS, private healthcare organisations and charities.

Mental Health Act Commission (MHAC)

We help people who have mental health problems and the Mental Health Act says they must stay in hospital to get treatment. Our job is to keep them safe.

What is this report about?

In 2008, the Commission for Social Care Inspection, the Healthcare Commission and the Mental Health Act Commission looked together at how councils and primary care trusts planned and bought services and support they needed. (This is called commissioning).

This is our Easy Read national summary report on what we found.

Why did we do this Joint Review?

People with learning disabilities and complex needs, although having more disabilities and needs than other people, should still be able to live full and independent lives and be part of their local communities. They should also benefit from the same rights as everyone else.

They, and their family members, can make their own decisions and should be supported to live their lives in the way they wish.

To make this happen, people and their family carers should be involved in planning their own care and support.

They may need to be able to get lots of different types of expert support. They should be able to get this easily and fairly.

There have been many reports about services for people with learning disabilities and complex needs showing that support is poor and should get better more quickly. These reports include:

‘Death by Indifference’

This Mencap report in 2007 highlighted how poor health services contributed to their deaths of some people with learning disabilities.

‘The Michael Report’

This was a detailed look in 2008 at how hard it is for people with learning disabilities to get good health services.

The Mansell Report

This report looked at services for people with learning disabilities and challenging behaviour or mental health. It said that people were often getting the wrong type of services, often away from home which cost a lot of money.

These and other reports made us worried that people with learning disabilities and complex needs and their family carers were not being supported to live good, independent lives.

It is the job of local councils and primary care trusts to work together to plan and buy services. We wanted to learn how well they have done so far.

We want this report to show others what we found and what needs to be done. We want this report to make life better for people with learning disabilities and complex needs, more quickly.

How we did the Joint Review

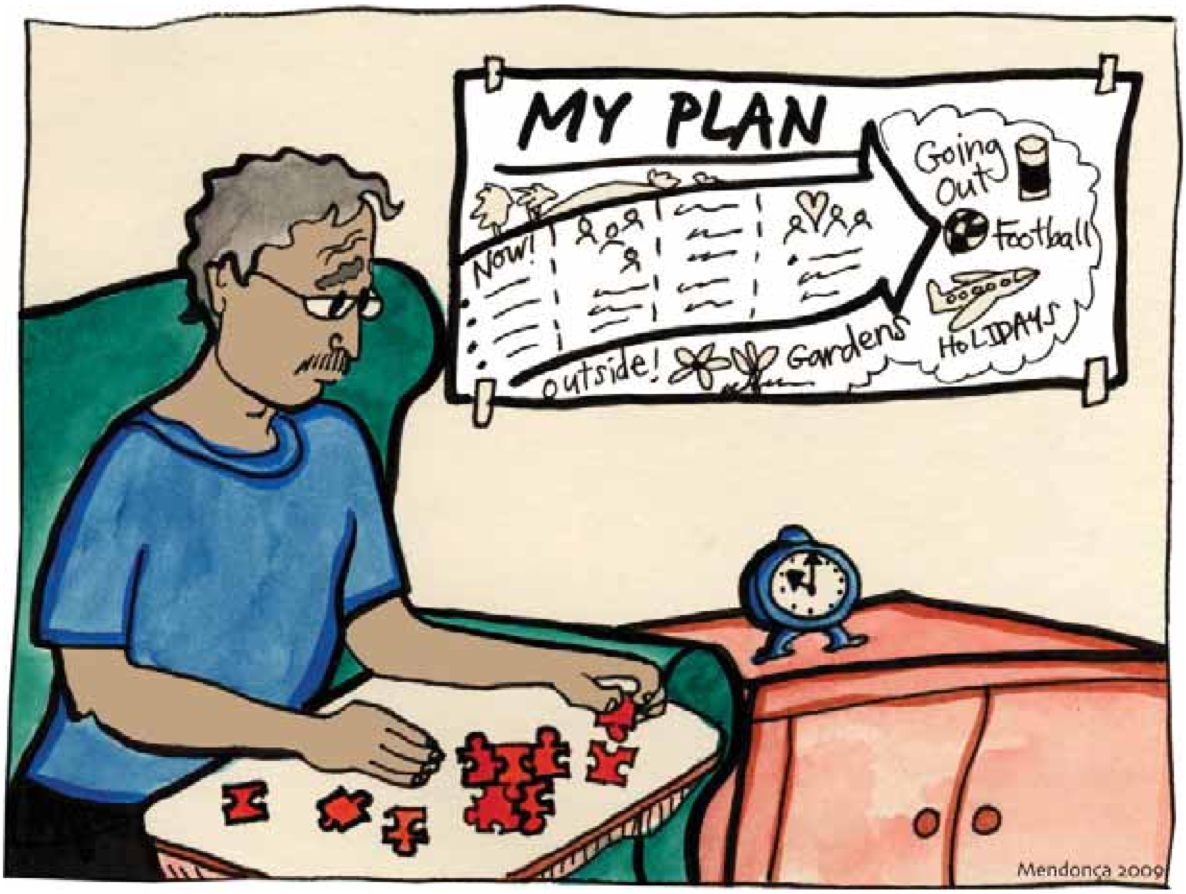
We had groups of people called Review Teams.

They visited nine different areas in England. They went to find out how councils and primary care trusts, in those areas, were planning and buying services and support for people with learning disabilities and complex needs.

Each review team included an expert by experience, which is someone who uses services; a family carer of a person who has complex needs, a commissioner who already buys people's services and support; and people from each of the three Commissions.

The review team used different ways to find out what was going on. These included spending time with people using services, going into places as a 'mystery shopper', having interviews and bigger meetings with people, and having an open session that anyone could come to.

We also either went to a Learning Disability Partnership Board meeting or met with people who were on these boards.



What we found

Overall, we found that staff were trying hard to make a difference to the lives of people with learning disabilities and complex needs. But much more needed to be done and more quickly.

People’s rights

1. Person-centred plans

People with learning disabilities and complex needs should have person centred care plans that fit their individual needs. Each plan should support them to live a full life.

Where there were good plans and these were being acted on they were making a real difference to people's lives.

But we found that many people had poor plans or didn't have plans at all.

2. Direct Payments

Since 1997 people who use services can ask to have Direct Payments so that they can plan and buy services and support for themselves.

Even though councils were doing lots to tell people about Direct Payments, not many people with learning disabilities and complex needs were getting them. Many people told us that they would like to get them.

Advocacy

People who find it hard to talk to other people should have good advocacy services. Advocacy is when someone finds out what you want and speaks for you.

Many people and their family carers could not get good advocacy services.

They also found it hard to get information that they could understand about advocacy services.

3. Family carers

Lots of family carers did not have assessments of their own needs. There was not a lot of support for them, such as short-term breaks.

Only a few family carers were involved in planning services and saying what the services were like. Where this happened it was good.

Plans for the future

Councils and primary care trusts had plans to make the services better in the future. But the plans were not clear or strong enough for us to know whether they were good.

Joint Strategic Needs Assessments

These are assessments that local councils and primary care trusts have to do together. They show what the people in their area need and how councils and primary care trusts are going to plan for services.

We found that they did not know enough about the needs of people with learning disabilities and complex needs. This lack of understanding made it hard for them to plan for the future.

Feedback about how good services are

Many people with learning disabilities and complex needs and their family carers told us that the council and primary care trusts did not take their views seriously.

Agreements with organisations that provide services

Some agreements (contracts) said that service providers must show how they were making a difference to the lives of people. Agreements were becoming more about individual people rather than having one agreement covering lots of people. This is good.

Services

Many councils and primary care trusts bought services that fitted people's needs better, but there was still more to do.

Housing

People were getting better housing choices than in the past.

Some people also had better day services and things to do.

Jobs

Very few people with learning disabilities and complex needs had jobs.

Health services

Lots of people with learning disabilities and complex needs had problems with health services:

- Not many had Health Action Plans or a health service worker (facilitator).
- Very few got annual health checks from their doctor.
- People and their family carers had bad experiences of services while they were in hospital. (This is about ordinary hospitals).
- Many could not get access to mental health services.

People from minority Ethnic communities

People from minority ethnic communities needed services to fit their needs. There were few services that were specially bought for people from these communities. When we saw some services that were bought just for a specific group of people there was a big difference and people valued such services.

Keeping people safe

Different ways to keep people safe need to be better. There were still plans and ways of doing things that were not good. As these individuals use services and support more, this is a worry.

Making it happen

Top managers were trying hard to make services better for people with learning disabilities and complex needs.

Many learning disability partnership boards were not doing enough to check that things were getting better for people with learning disabilities and complex needs.

Community learning disability teams were not always giving a joined-up service.

Many staff working in social care, health and other public services did not know enough about people with learning disabilities and complex needs to give them a good service.

What needs to happen

Top managers were learning from the reports about poor services but changes were not happening fast enough.

We are worried that things are taking too long to change.

There are lots of information and guides on how to make things better. Now we also have:

Valuing People Now

This is the Government's plan of action for people with learning disabilities in England.

It sets out a way for lots of different people and organisations to work together to make the lives of people with learning disabilities better.

Services need to do what this and other documents say, urgently.

Councils and primary care trusts need to make sure that everyone works on these problems to make things happen faster.

Ten big things that need to happen

We have put ten big issues (challenges) that everybody needs to think about. These are:

1. Person-centred plans, health action plans and advocacy must happen. Everybody has the right to them and they should not be seen as add-ons.

   Councils and primary care trusts should check whether they are planning and buying services that meet individual needs, so that people with learning disabilities and complex needs are better served.

   This may mean making changes to things that others may not need. This is called 'reasonable adjustments'.

2. Service providers should do more to get people with learning disabilities and complex needs and their family carers involved in planning and saying what they think about services. Providers then need to make sure they act on this information.

3. More people should get the chance of Direct Payments and personal budgets to plan and buy their own services.

4. Health and social care organisations need to get better at sharing information so they can see how well they are doing to meet the needs of people with learning disabilities and complex needs.

5. Most learning disability partnership boards are not working as they should. They should be supported to do more.

6. Councils and primary care trusts need to make sure their Joint Strategic Needs Assessments have the right information so that things get better for people with learning disabilities and complex needs.

7. Community learning disability teams need checking to see if they are working properly.

8. Primary care trusts must check that they have made it easier for people with learning disabilities and complex needs to access health services and that these services meet their needs.

9. Councils and primary care trusts need to make their ways of keeping people safe a lot better for people with learning disabilities and complex needs. This is urgent.

10. Many staff, especially staff working in health, need more training to learn more about people with learning disabilities and complex needs. Many staff need to change the way they think about people with learning disabilities and what they can achieve with the right support. They also need to be reminded about the law to make sure people's human rights are being met.

    We expect that services and support for people with learning disabilities and complex needs will get better if:

    - everyone works together
    - plans are made well
    - people and their family carers are fully involved in their support and services.

What the three Commissions would like to see happen

This is one of our last reports before the three organisations become one which is called the Care Quality Commission (CQC) (April 2009).

We have three overall points that we want the health and social care organisations and the new Care Quality Commission to do to support Valuing People Now.

1. NHS and social care people must make sure that the way they plan and buy services is the same as what Valuing People Now says and is meeting people's needs.

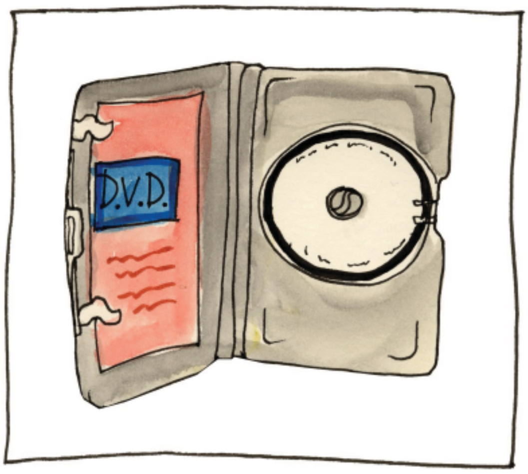
2. Councils and the NHS should make sure that all services and support are personal to the individual. All services and support no matter where this is taking place must be shaped around the person who is using them. This is called personalisation.
3. We would like CQC to check that people, who plan, buy and provide services are giving what is needed to people with learning disabilities and complex needs.

The CQC must say which councils and primary care trusts are not doing well enough for all people with learning disabilities and expect improvements.

Thanks

We would like to thank all the people with learning disabilities and complex needs and family carers who helped us to make this report.

More Information



For further copies of the Easy Read report, and for our DVD about the joint review, please contact us (see back cover).

We will also have some video clips on YouTube which can be seen on our channel (search for 'healthcarecommission' on YouTube).

You can see the nine easy read reports on our websites
(see back cover).

From April 2009, the Care Quality Commission will take over the work of the Commission for Social Care Inspection, the Healthcare Commission and the Mental Health Act Commission. Website: www.cqc.org.uk

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