



Report on the White Paper: Liberating the NHS – Equity & Excellence

A group of self advocates from North Lincolnshire and Debra Moore met to talk the new White Paper Equity and Excellence – *Liberating the NHS*.

We met to think about the paper and asked ourselves the question “**how might the White Paper impact on people with learning disabilities?**”

This paper tells you the things we talked about and some of our ideas.

The White paper includes quite a lot of new ideas for changes to the NHS for everyone in the country.

We have put these ideas under headings that cover the ‘big themes’ to help people think about the issues for people with learning disabilities.

Changing the way that the NHS is organized and strengthening local partnerships

There are some big changes planned for the way that the health services are bought and run.

Organisations like Primary Care Trusts and Strategic Health Authorities will stop and new organizations will be put in their place.

One of the main changes is that they will give more power to GP’s to buy the services that people need in their area.

They will have groups of GP’s to work together in **commissioning consortiums**.

This means a group of Doctors working together to decide what health services they want to buy for people in their area.

These groups will have control of most of the money there is to buy health services.

Some specialist services will be bought by a new national **NHS Commissioning Board**.



As well as these new groups who will decide what services to buy there will be other changes to how health and social care services work together.

The White paper says councils will get new things to do including making sure there is good public health work and 'health and wellbeing boards' that think about everyone's health.

What might this mean for people with learning disabilities?

It will be important that the groups of GP's buying services include skills, knowledge and information about people with learning disabilities so that they make good decisions.

They will need to make sure they know what to do to reduce the health inequalities faced by people with learning disabilities – this means making health services fairer and safer so people with learning disabilities have the same chances to be healthy.

There have been a lot of reports and inquiries like those by the Disability Rights Commission and Mencap that show the problems that people with learning disabilities have had in the NHS.

A lot of this is because doctors and other health staff did not know enough about people with learning disabilities or understand how to work with them.

The white paper also has ideas about what patients ask for showing what services need to be bought.

If this will work the groups of GPs will need to make sure they find out what all **patients** think about services including people who might not be in regular contact with the NHS such as people with learning disabilities in prison.

If Local Authorities are in charge of public health and do more work around health and wellbeing we think this should be good for people with learning disabilities.

Local authorities already work on wider issues that affect good health and wellbeing such as employment and housing.



One of the big changes will be new people buying services and working with the people who run the services.

We think it will be important that when the changes happen they try to make sure it does not stop the services working well for people who use them.

Changing the culture of the NHS

The white paper says there will be changes to the way we check how good health services are.

It is going to focus on quality of the services and the difference they make.

It also says that patients and health professionals will have a greater say in deciding if services are good and what needs to improve.

The 5 big target areas will be

- Stopping people from dying early
- Making the quality of life better for people with long term conditions
- Help people get better after ill health or injury
- Making sure people have a positive experience of care
- Making sure people are safe and protecting them from harm

They will use different ways to measure progress including patient surveys and questionnaires that check how much has changed from the patient's point of view

What might this mean for people with learning disabilities?

Health services should get better for People with learning disabilities with the work on the 5 big target areas especially ones like making sure people are safe in hospital.

We know from research that these 5 big targets areas are really important things for people with learning disabilities and their families.

Asking people what they think of services is also good but we are a bit worried that people with learning disabilities might not be asked what they think. This is because of the ways that they ask patients what they think.





For example not everyone can say what they think using a survey.

It will also be really important to make sure they ask family carers and advocacy when they are checking on these 5 big target areas and especially when they ask about a person's quality of life.

Also, some people with learning disabilities have high cost packages of care to support them as their needs are complex and their care is really person centred.

It will be important to make sure that the groups of GPs buying services understand about these packages of care and that it does not become more likely for people to have to get support in big groups only.

Looking at the difference health services make for patients and what people think about their care was is a good idea.

But it will not be good if they do not do it in ways that make it easy for people with learning disabilities to take part.

This would mean providing accessible information about what they will expect will happen in hospital and what standards are in place. Sometimes people don't complain about poor treatment because they think it's the same for everybody or they don't understand their rights as a patient. Also sometimes people ask people what they think using hard to understand surveys that are not accessible.

It will be important when the health services look at what people have said they make sure

- they know how many people with learning disabilities had their say
- what those people said
- How different the service they had from other people. For example It might be that a hospital provides a good service for one group but not another.

When what everyone has said is shared it needs to be in a useful format and accessible to everyone.

For example there is already some information about what people think of services but often it is on the internet or in long reports and includes hard to understand tables and graphs.



Putting patients at the heart of the NHS



The White paper plans to make sure that people are able to make choices and decisions about their own care. It says “no decision about me without me”.

Patients will be given information about services to help them to choose where they would like to get treatment. This will include choice over maternity care, mental health, long term conditions and end of life care.

Pilots of personal health budgets will carry on and how good they are will be checked in 2012.

There will also be a new organization called ‘Healthwatch’ that will say what patients think. It will be part of the Care Quality Commission.

What might this mean for people with learning disabilities?

‘No decision about me without me’ is a bit like people with learning disabilities say in ‘Nothing about us without us’ and so it is a really good thing that everyone will be able to make choices and decisions.

But we know that the NHS already finds it hard to communicate with people with learning disabilities. We think there will need to be training and support for health professionals to make sure that they are able to include people with learning disabilities in making choices and decisions about their own care.

It will be really important that all health professionals have a good understanding and knowledge of good practice around Mental Capacity and that people’s decisions are respected.

We know from the Mencap reports that what family carers know and think is really important but a lot of the time they are not included in making important decisions. This is really important for people with more profound and multiple intellectual disabilities.

It will be important that people can help from advocacy but we do not know yet if the changes to how health services are bought will change how people get advocacy support.

Choosing where you get treatment will be hard to get right for people with learning disabilities.



In some areas there may be only one service people could use and for some specialist services you may have to go to another area or town.



People with learning disabilities should get a better service if they can choose where to get treatment for things like

- mental health,
- maternity – having a baby
- long term conditions
- end of life care – when someone is dying soon

We think this will only mean people get better health services if people with learning disabilities are included in thinking about and planning local healthy services.



We know that sometimes people cannot easily use services like maternity and mental health already so 'getting the basics right' will be important.

Information about how good services are and how they work does not always say what it is important to people with learning disabilities. Information will need to be accessible and available in different places **not just on websites.**



Here are some of the 'headlines' of our big discussion

- There needs to be more training and awareness of learning disability in the NHS generally. It is worrying that GP's who will have most said in how money will be spent get very little training in learning disabilities.
- Having a choice of doctor is good but people often like to see the same doctor and build up a relationship. They need to think about this when they are planning how services will be run.





- What will happen to advocacy services – how will they be funded? As money moves to GP's and people get personal budgets how will these services be bought?
- How will we make sure people get good support after they have been in hospital? For many people with learning disabilities things can go wrong when they leave. People don't always get information about what to do when they go home after surgery etc.

- How will we make sure that the information people have in health action plans and hospital passports is included in the new systems. Some people have plans now but staff in health services don't always read them or follow what is written.



- Local areas often have people with learning disabilities who have experience of 'checking' health services – we need to build on this and help it happen more.
- What about specialist learning disability health services. How will they be bought and planned? We need to make sure that people can get access to expert support when they need it.
- Some people with learning disabilities have very complex needs. How will we make sure that GP's understand their needs and are able to plan and buy all the different health services they might use.