

Easy
Read



More Information, Less Medication

Improving the use of psychotropic drugs
for people with a learning disability.

Executive Summary

September 2016

Background

Research was done to find out why the number of people with a learning disability who are given medication for mental health issues is going up.

CHANGE asked people with a learning disability to talk about their experiences with taking medication.

They did this by giving out surveys, running focus group at mental health hospitals and doing research.

CHANGE spoke to patients, ex patients and mental health professionals to ask them about their experiences.



2016



NHS England supported CHANGE and the Patient Information Forum to do this.

Our Aim

We wanted to make sure that people with a learning disability led the project.



We also wanted to find out how much people with a learning disability understand about their medication.



We want to support mental health professionals to work and communicate better with people with a learning disability and involve them in their care.



We want more people to know the views and experiences of people with a learning disability.

We want to support NHS England to help people with a learning disability and find out what they think.

What we found out

We found that professionals do not always have accessible information that they can give to patients.

Sometimes people would prefer for someone in their family to keep taking their medication.



We found out from people with a learning disability that they do not always get to talk to staff about their medication on a one to one basis.



Many people we spoke to did not know the name of the medication they were taking or the side effects of the medication.



Many people also said they could not understand health professionals. This was often true for patients who could not communicate verbally.



Many patients in hospital did not know how to make a complaint about their care. Some patients did not have this explained to them.



Most of the people with a learning disability said that they had never seen their pharmacist and that doctors only visited them sometimes.



People with a learning disability said that they were not allowed to say no to taking their medication without a doctor saying it was ok. This made some people feel scared.

Recommendations



We made some suggestions to NHS England, based on what people with a learning disability told us. These are:



1 Peer Support

We said that it should be easier for people with a learning disability to get peer support in health services.

Peer support is when a person with a learning disability uses their experiences to help another person with a learning disability.

Peer support can also help people to have more confidence.

Peer support can also help people with a learning disability have stronger support networks.





2 Access to activities

We said that people with a learning disability should have quicker access to activities that help their mental wellbeing.



Research shows that if a person with a learning disability is able to access activities, it can have a positive effect on their physical health and mental wellbeing.



Some examples of activities are drama or gardening.



It could also be getting support, like counselling.



These activities can also support people to move from a hospital back into the community.

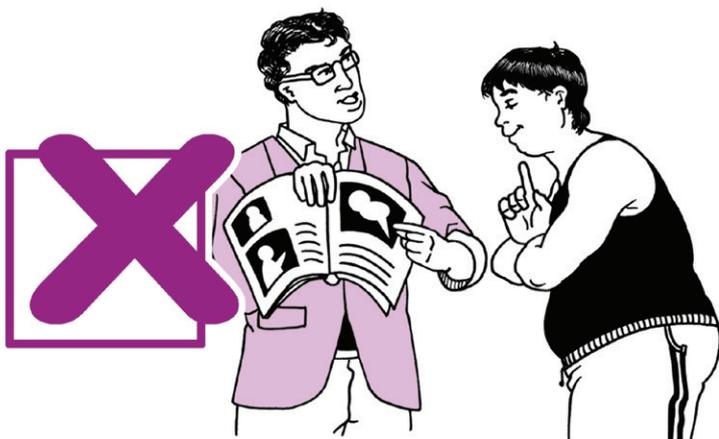
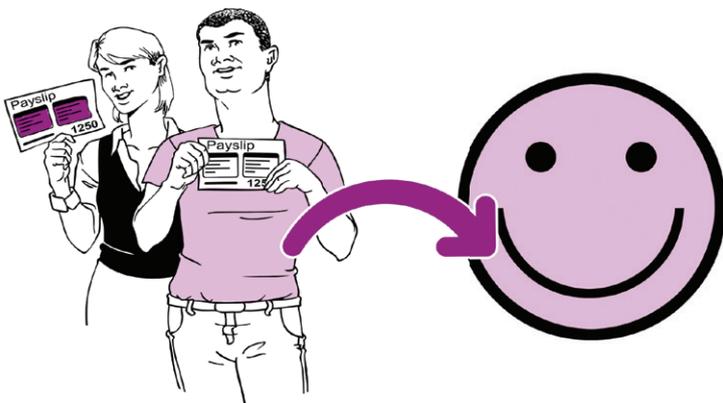
3 Learning disability leaders

We also said that the NHS should employ more people with a learning disability to train and advise health care professionals. They could advise them about accessible information and communication.

Research says that there is a strong link between employment and positive mental health, but very few people with a learning disability have a job.

4 Accessible Information

We said that all services should provide accessible information in a way that the patient understands. This is to make sure that people with a learning disability understand changes about medication.





Accessible Information is important because people with a learning disability may not have a good relationship with health professionals.



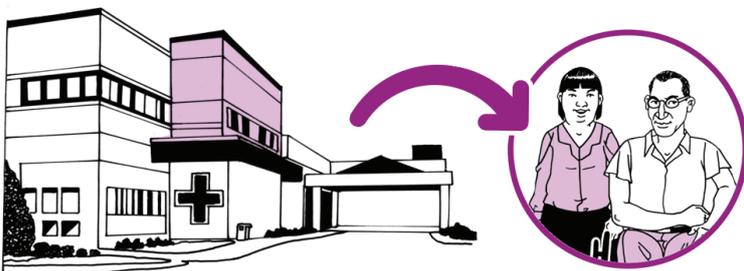
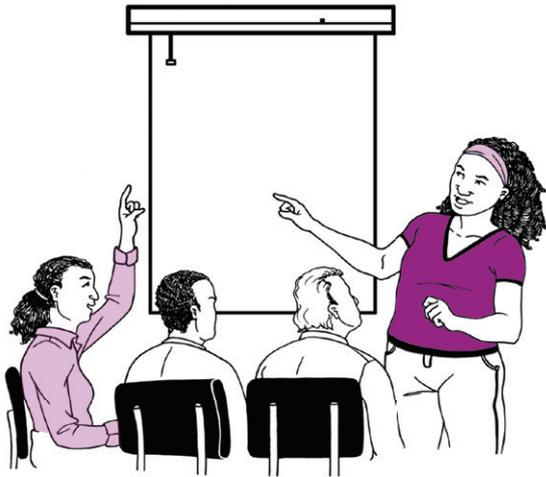
Providing accessible information will help people with a learning disability to understand their medication and ask questions if they want to.



This advice is based on the **Accessible Information Standard [2016]** which says that the NHS services must provide accessible information that meets a person's needs. This is part of the law and must be followed.



Medical professionals should also spend time getting to know patients and help them to understand the information they have been given.



5 Accessible Training

We think it is a good idea for all professionals to be trained by people with a learning disability. The training would be about how professionals can communicate better.

People with a learning disability should also have access to training and support to understand their rights and medication.

Patients should also get help to find out how to make a complaint if they are not happy and if things go wrong.

6 Working with self-advocacy groups

We also said that health services should work with self-advocacy groups to give support to people with a learning disability.



Making strong links between advocacy groups and health services is important for people with a learning disability that have moved back in to the community.

This can make sure that people with a learning disability have stronger support networks in their communities.

Self-advocacy groups can also support services by quality checking services and the information which is given to patients.

Conclusion

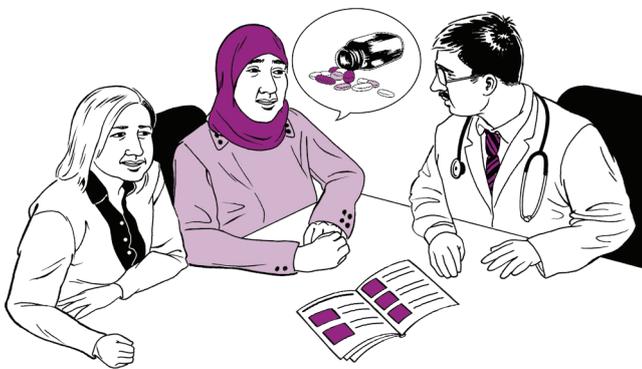
We found out that a lot of the problems for people with a learning disability and their medication is that they do not understand the medication they are taking and the side effects.



Not having accessible information also makes it hard for people with a learning disability.



Sometimes, professionals didn't spend time helping a person to understand the information they were given. This is because they didn't think a person with a learning disability could make their own choice.



This report can help professionals find out how to work with people with a learning disability in a better way.



If a professional gets to know a patient and communicates with them in a better way, they can stop people from being over medicated and having to go back to hospital.



Every patient has a right to have control over the medication they take and the treatment they get.

If you would like support, or more information about the project, you can visit our website.

www.changepeople.org

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