

**Easy
Read**



Making Health and Social Care Information Accessible

**Easy Read Report about the focus groups
for people with learning disabilities run by
CHANGE
2013/2014**



Making health and social care information accessible

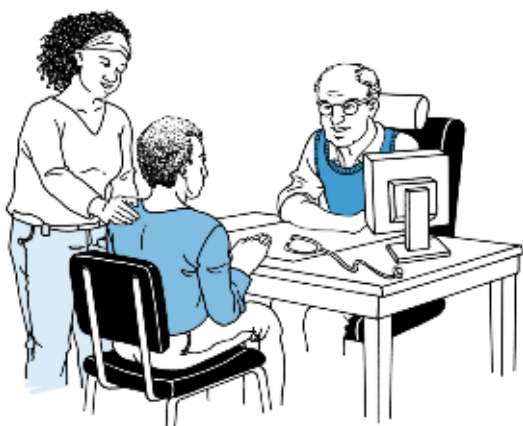
Easy Read Report about the focus groups for people with learning disabilities run by CHANGE



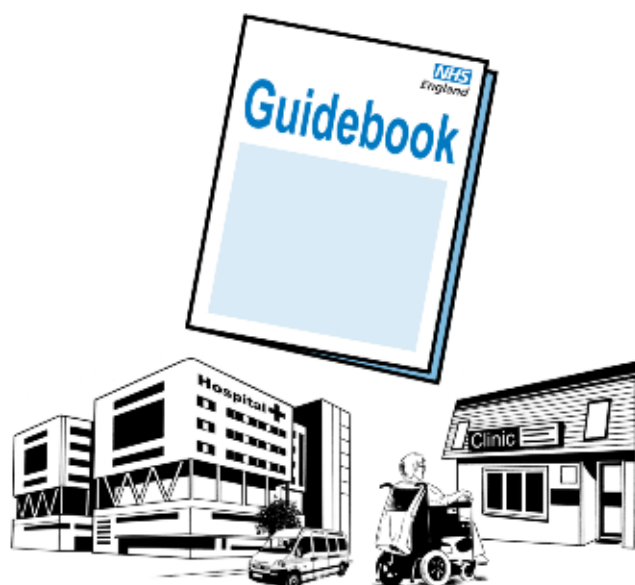
NHS England's main aim is to improve people's health.



NHS England want to make sure that people can understand the information they get about their health and care.



They also want everyone to be able to get involved in decisions that affect them.



NHS England is writing a new guidebook for NHS and social care organisations, such as your doctors, hospital or council.

This guidebook will be an Information Standard. This is a set of rules which organisations must follow.



NHS England wanted to know what people thought before they wrote the guidebook. They asked CHANGE to run 5 focus groups to help find out what people with learning disabilities thought.



This report tells you about the focus groups. It tells you the key things that people talked about.

What we did and how we did it



CHANGE worked together with self-advocacy groups and organisations that work with people with learning disabilities, to find people across the country who could come to the groups.

We held focus groups:

- in Leeds on 21 November 2013
- with Grapevine in Coventry on 3 December 2013
- with Elfrida Society in London on 9 December 2013
- with North Somerset People First in Weston super Mare on 10 December 2013
- with Skills for People in Newcastle upon Tyne on 16 December 2013.





The focus groups were led by a project worker with learning disabilities working together with a project worker without learning disabilities.



We gave people easy read information about the focus group before they came. We asked people to give their consent to coming to the group. Consent means agreeing to something.



We explained hard words. We used easy read information so that everyone could understand and take part.

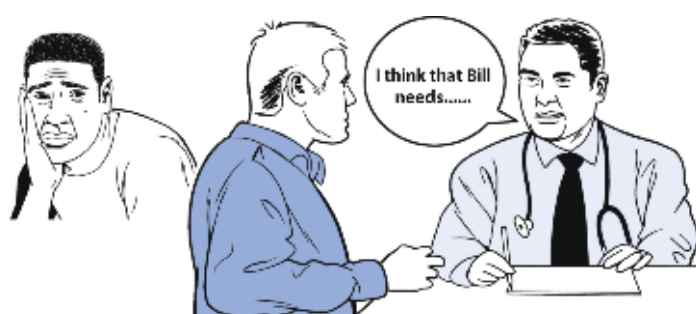


In total, 61 people with learning disabilities from all over the country took part.

What people said about the support they need when they meet with health and social care professionals



- People often need support when they go to the doctors or when they talk to health and social care professionals. They often ask a family member, a friend or a support person to go with them.



- Sometimes this works well. But often, the doctor or other professional will talk to the support person. They don't always talk directly to the person with learning disabilities. This makes people with learning disabilities feel angry and upset.



- Some people told us that they had to wait for their support person to come before the doctor would talk to them or give them treatment. People with learning disabilities thought that this was very bad.



- Most people with learning disabilities want to have more time when they see a doctor or other professional. People with learning disabilities think that having time to talk is an important part of being given respect.

- People with learning disabilities often find it very hard when there are lots of changes of worker. They said that there are often lots of changes of workers in social care.

- People with learning disabilities don't want to have to say the same thing over and over again to professionals. They want doctors and professionals to read their records before they see them.



- Little things make a big difference. Things like photos of doctors in waiting rooms and accessible signs are very important.

What people said about getting the right information at the right time



- Everyone said that there is not enough easy read information. Only a very few people said that they get easy read letters telling them they have an appointment.



Only a very few people had been given easy read information about their medication and the tablets they take. This is a very big gap.



- People said it would make a big difference to their lives if they got the right support to communicate and if they got easy read information. People with learning disabilities said this would give them more control over their lives.

They said that if they had the right information, they could look after their own health better.

One question about your communication needs?



- NHS England thought it might be a good idea if everyone was asked the same question when they went to the doctors, or hospital or the council.



- NHS England wanted to find out what people thought of this question:

“Do you find it difficult or do you need support to see, to hear, to read, to speak or to understand what is being said?”

- Lots of people with learning disabilities were not sure about this. Some people were worried about who would ask this question and how. People with learning disabilities want to make sure that their privacy is respected.

- Most people with learning disabilities said that this question was too long and too hard to understand.

Should health and social care organisations share information about people's communication needs?



- People with learning disabilities want to be asked before professionals share information with each other.
- People with learning disabilities thought that health passports could be used to help professionals understand what people's needs are.
- Some people with learning disabilities had been involved in training health and other professionals. People with learning disabilities felt very strongly that this is a good way to change the way that they are treated by professionals. They felt it was a good way to make services better.

Summary



This report is a summary.
This means that we have put everyone's views together.
This report has the key points.

CHANGE has also written a longer report for NHS England. This is to make sure that we have included what everyone said. We did not want to miss out what people told us about their experiences. These are very important.

You can read the longer report and find out more about NHS England on this website:



We want to thank all the people with learning disabilities who took part for their time and talking to us.



We want to thank these organisations who supported us in holding the focus groups:



Grapevine

Grapevine is a charity helping people with learning disabilities to grow their lives.

www.grapevinecovandwarks.org/



Elfrida Society

The Elfrida Society is a leading charity based in Islington London for adults with learning difficulties.

www.elfrida.com/



North Somerset People First

NSPF is a self-advocacy organisation for people with a learning disability.

www.listentoourviews.org



Skills for People

Skills for People supports disabled people and their families.

www.skillsforpeople.org.uk



CHANGE

CHANGE

CHANGE is a leading UK based human rights organisation led by Disabled People.

www.changepeople.org

