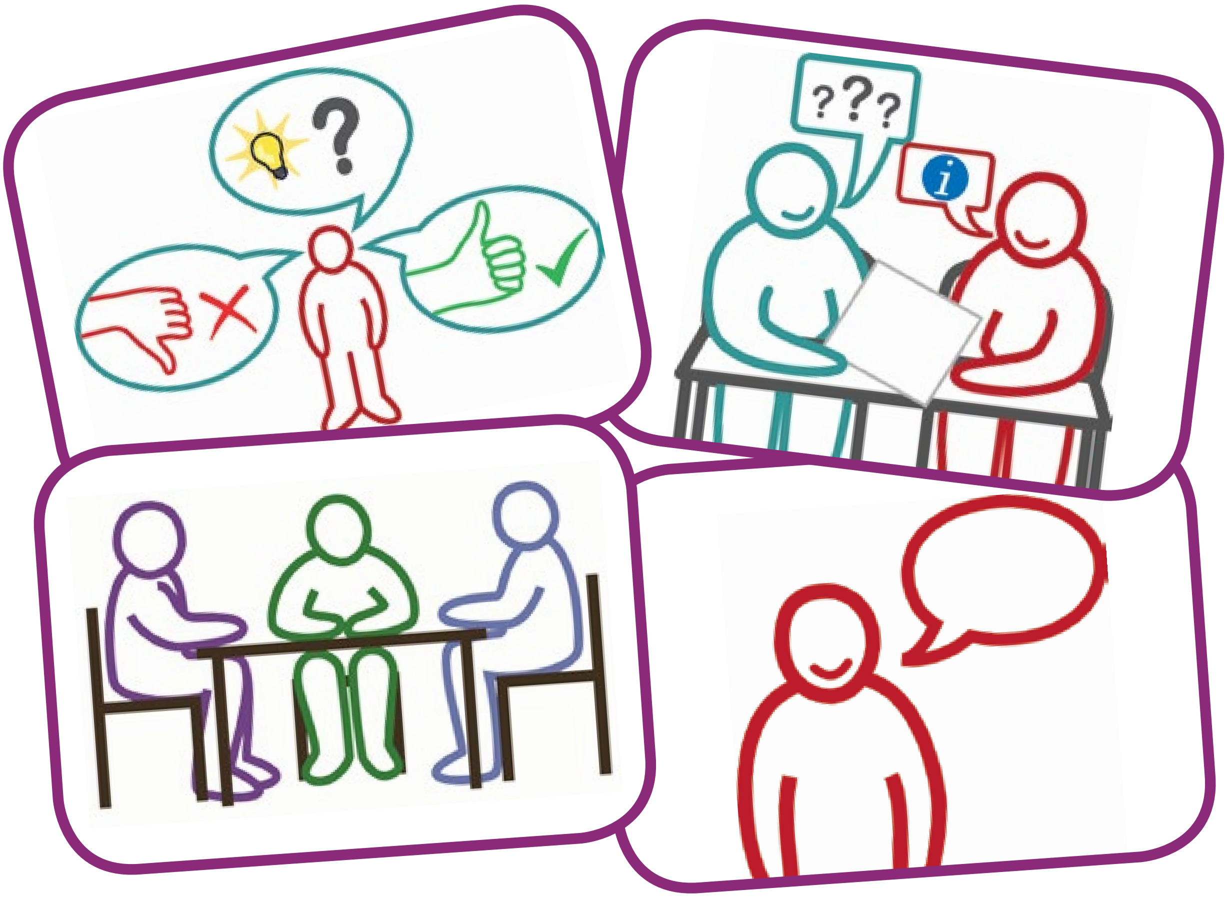
Reach Report

No Voice Unheard, No Right Ignored
Consultation - June 2015



Reach is part of asist advocacy services in staffordshire

Introduction

Reach is a group advocacy project supporting adults with learning disabilities in Stoke-on-Trent and Staffordshire to speak up about their lives.

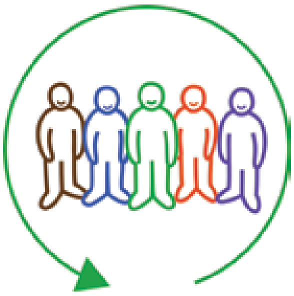
In May 2015, Reach supported people to speak up about the Department of Health consultation **No Voice Unheard, No Right Ignored**.

Reach supported people to answer the 14 questions in the ‘easy read’ version of the consultation (Making Rights Better and Listening to People).

Reach project workers used the ‘easy read’ information and made posters that explained the consultation, helping Reach members to look closely at the questions and think about their answers.

Reach members wanted to share their thoughts and ideas instead of just giving ‘yes’ and ‘no’ answers to the consultation questions.

Introduction



Reach members shared their thoughts, ideas and experiences and also talked about the consultation questions and information.

Altogether, Reach held **7** small focus group meetings supporting **13 adults with learning disabilities** to speak up about the consultation.

Reach also supported 2 of those people to attend the West Midlands Regional Forum meeting on the consultation.

All the things Reach members said - in their own words - about the consultation were sent to the Department of Health at the end of May 2015.

This clear information report highlights some of the main things Reach members said about the consultation.

Question 1 was about people with learning disabilities and autism who need lots of support from the NHS and social care services.

Question 1 talked about people's wellbeing and asked if they should get treatment and services close to home and in their community.

Reach members said...

There's too many in hospitals. They should be near friends and family. I've got a family. I've got a mum.

I agree they should stay closer to home but with all the work the NHS have to do, and the way funding is, will they have services nearby?

They really need improve things for people who've just been discharged from mental health services. I've been discharged and just had no support when I left. There needs be somewhere you can go and talk to someone. You need services in the community.

Make more services, don't cut. Close to friends, family, communities.

Reach members said...

The support's not there. Not unless you've got loads and loads of problems and needs. You get missed out. You don't get the support.

You want the best care and wellbeing for the person that's got the mental health problems and having their family nearby will be better for their wellbeing.

To me, it's a load of rubbish. They should be helping people with their wellbeing, be well already, NOW.

There are not good services in the community at the moment. It's to do with funding. They can't find places for people.

Important to stay within your community.

Question 2 was about people knowing their rights, having a say and being able to say 'no' if they aren't happy with decisions made about their treatment and services.

Reach members said...

People need be comfortable telling carers and social workers they're not happy with their care.

They should ask you. Everyone's got a right to say what should happen to them.

Of course they should ask people.

I agree with that way of life.

You should have more say and support.

People need information they can understand to help them make choices.

If you know your rights you can make decisions about what you want – your own choices and decisions.

You have the right to challenge but you're not always told that, and you're not always well enough (with your mental health) to do it.

Question 3 was about speaking up, involving people and their advocates.

Reach members said...

Reach helps me to have my say. Advocates from Asist as well.

They, the learning disability people, they're living with their disabilities. They need be on boards. It's appalling if they aren't the ones having a say and running services. It's not their fault they've got their type of illnesses.

Working together. It's very important.

People need to have training to take part, use their lived experience.

That all sounds good on paper but I don't think it will be done. That'd be brilliant in a fantasy world but when budgets are tight, it'd be the opposite.

People should have the same power as commissioners to choose as well. I am better to choose because I lived it.

Question 4 was about helping people have their rights respected, and having support from family, social workers and advocates.

Reach members said...

My social worker left so when I had a review it was with a temporary social worker who didn't...

... know me. I wasn't happy because you should have a named social worker.

Advocates give people time and listen.

If I wasn't happy with my social worker I'd say so. I think they can be quite pushy. They don't always explain what they're doing or why. They should explain things to me, involve my family, talk to them as well.

This should all be in place already anyway.

Advocates, IMHAs, social workers all give good support for people to speak up and get information across to people if they struggle.

Question 5 was about helping people to speak up if things go wrong with their care, treatment and support.

Reach members said...

Services should all have a complaints service like PALS you can go to. It's important have the right person complain to, someone separate from the person you're complaining about.

It's more better to complain now [than it used to be].

Complaints system can be very long-winded. It takes a long time resolve things.

I'm not sure they really do anything when you complain.

I don't think it's easier to complain now. It's harder. I never get the help to make a complaint.

To make it better – could have pictures, accessible complaints forms and leaflets telling people how complain.

A lot still needs be done to make it easier to complain.

You need to have complaints and advocacy services open at the weekends so you can get support when you need it.

Question 6 was about people's rights under the Mental Health Act.

Reach members said...

Everybody has got their rights. It's hard because I do like saying and speaking...

... up about my rights but sometimes people don't ask me what I need.

People don't tell you about your rights.

It's wrong to put them in prison or hospital. It has a bad effect on their mental health and hurts their wellbeing. It makes them scared and anxious, upset and confused. People should be treated in the community with friends, family, people close by.

People with learning disabilities and autism need a lot more understanding off services.

People don't know what's happening to them.

Question 7 was about making the Mental Health Act easier to understand and make sure people have one set of rules for assessment and treatment.

Reach members said...

They need make it clearer. Make it so people can understand. If a law's that complicated, it should be made easier to understand.

Will one path work? I think stuff like this should be done based on the person, their needs, not rules.

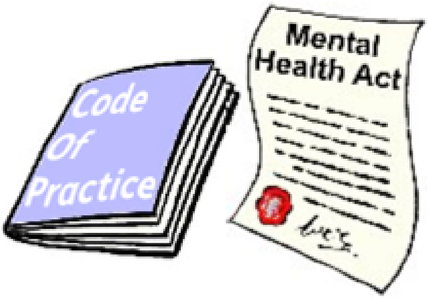
It'd be better if things were easier to understand but there are differences between people.

If you've got 40 different sets of rules, how are you going work out what's happening and what everyone is doing?

Different needs and experiences. Not everybody is the same.

It's very important to have the Mental Health Act easier to understand for people with learning disabilities and mental health and be confident about.

Question 8 was about the Code of Practice (a set of rules) about how the Mental Health Act works.



The government are planning to change the law so commissioners (people who plan and buy services) have to follow the Code of Practice as hospitals do.

Reach members said...

Everyone should follow the same set of rules. If they have to follow rules it should make things better, services getting better, working well in their area.

You need to be careful changing laws. It needs to work for everyone.

They should all follow the same rules. If they all have the one set of rules then it wouldn't be so confusing.

Question 9 was about using prison cells as 'places of safety' and people being held in hospitals instead of prison.

Reach members said...

I've been in a police cell because the hospital was full. I was there for...

... ten and a half hours, in handcuffs all the way, no medication in me and I...

... didn't see anyone from social care. I had to wait another three...

... hours to see someone from the crisis team.

Need to understand people's needs and have support from health services not police, or work together. Police can make situation worse.

Police cells are not a place of safety. Can be places of danger, people harming themselves.

No one should be held in a police cell because they are not well – they have not done anything wrong.

Police cells should be for bad people, not people with learning disabilities.

Question 10 was about people with autism and learning disabilities using Personal Health Budgets.

Reach members said...

Will it work, having a personal health budget? It hasn't gone so well with normal personal budgets in social care has it?

It's a good idea but it sounds complicated, can you get help with it? If not it will be too hard.

Personal budgets and direct payments are helpful. Can choose what you want to do.

Will people actually have choice and control as part of care package?

There would need be more things out there to choose from if this is going to work.

Question 11 was about putting money for learning disability and mental health services together.

Reach members said...

What happens if they put all the money together and then it gets cut because someone thinks it looks like lots of money, you end up with less than you started with and that's really bad.

I would say people need a lot more money for their care and support.

If they put money together it will work together.

Need more money and funding for services – advocacy and community.

For me, being inbetween services (learning disability and mental health) you get nothing but arguing about funding and who pays.

Question 12 was about how services should share information about people with learning disabilities and autism.

Reach members said...

Services should know a lot more if it helps people.

I think people should be entitled to privacy. You should get to choose who knows information about you.

Important to share information to get the right care.

Person should have the right to tell and not tell people – own right – to keep people safe.

What information are we talking about? What are they sharing?

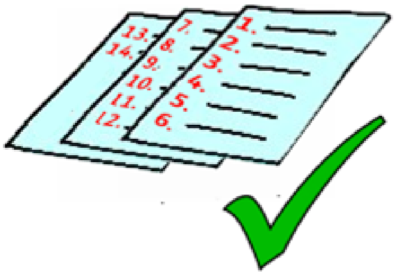
Question 13 was about making it clear who looks after the physical health of people in mental health hospitals and services.

Reach members said...

We don't know everything. We should know more. You should have more information.

This should have been done all along, people should know who helps you when you are not well.

It's not that important to know who pays as long as you receive the services.



Question 14 asked if there was anything else people wanted to say about the consultation.

Reach members said...

With the new Conservative government saying there's got to be more cuts where is the money going to come from for all this? It's all well and good saying you've got to have these services in the community and people getting care and support in their own home but where does the money come from?

The main thing – the reason they won't change all this is the finance.

The NHS should have good local services. People are not living as good as they used to.

Reach asked people to comment on the Department of Health ‘easy read’ information and the consultation.

Reach members said...

It was too long. It was boring, not interesting.

By the Gods, man that’s too much. Too much information to think about.

I couldn’t just go through this booklet. I need someone like Reach to explain what it’s all about and help me get through it.

There’s a lot of information in there I didn’t understand so I had to ask lots of questions.

Found this consultation hard to understand. Too much information.

The thing with these consultations is they send these papers out and they ask the questions they want to ask but they don’t change anything.

Contacts

Pictogram images used in this report were made by Reach.

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Reach is part of Asist, Advocacy Services in Staffordshire.

Thanks to Photosymbols for some of the images used in this booklet.