NHS England Forum for people with a Learning Disability and/or Autism, their Families, Carers and Supporters.

Friday 13 November 2015, Sheffield Town Hall

Summary Report

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1 Introduction

The NHS England Forum for people with a Learning Disability and/or Autism, their Families, Carers and Supporters met for the second time on Friday 13 November. This was the first meeting being led by the new Learning Disability Engagement Team.

The day was split into three parts:

1. Your view of the Building the Right Support - how we can make sure experts by experience are involved in planning services locally?
2. What good easy read looks like.
   OR
   How we should share information with you.
3. What NHS England's priorities should be.

This summary will cover three things for each part of the day:

1. What we told you.
2. What you told us.
3. What we are going to do next.

You can also see the photos that were taken on the day, here.

If you would like to get involved with the Forum, meet with us, or share your ideas please email the Learning Disability Engagement Team (LDEngage@nhs.net), follow @LDEngagement on Twitter or visit the LDEngagement Facebook page. You can also call us on 0113 8249686.

2 Building the Right Support

2.1 What did we tell you?

We told you about the national plan, Building the Right Support (Building the Right Support easy read). We told you that the government's plan is to spend more money on supporting people at home so that some hospitals can close. We told you that transforming care partnerships will work with local people to say how they will change local services. They must make the changes by March 2019. We want people to be listened to and involved to make decisions about their local services.

2.2 What did you tell us?

We asked the Forum three things about Building the Right Support:

1. What the 'bright future' would look like if reshaped services got everything right.
2. What the 'nightmare future' would look like if reshaped services got everything wrong.
3. How can we best involve people in designing local services

We had over two hundred comments. Here are some of the big ideas:

		
Think about me	There is person-centred planning, care and support. I can do things that I like, when I want (not just when it is on the day service timetable).	There is no person centred planning. People with challenging behaviour are all in one house.
Plan for success as well as difficulty	There needs to be forward planning and quick action. This would avoid the need to move a person away from their home.	Long waiting lists when urgent support is needed.
Choice of Service	Every child will be offered a personal budget and support to use it.	People have to fit around the services that are available.
Quality Service	Front line staff are accredited, resilient, well trained and well supported.	Hospitals are shut down and nothing is there to take their place. Instead money is spend on services that don't do what people want.
Support in the Community	Homes for life, not emergency rented accommodation. People would like to stay in the same place and not be moved.	Not enough houses.
Support for families and carers	Carers are supported and do not have to care too late in life (but will still be involved in the care).	Families do not have a normal family life – they are living in poverty, not working, lonely and not valued.
Families and carers are involved in designing local Services	Parents and families are considered the experts. There are actions, not more meetings and talks.	The people who know best (for example carers) are not involved and listened to.

Our Forum event would have been better if we had given more time for families and carers to share their stories. When transforming care partnerships involve families and carers it is important that there is enough time for people to share stories. It is also important that families and carers are involved in the process from the beginning – early enough to have a real influence.

How should your local area get people involved?

- Make time to listen.
- Talk to local learning disability and autism groups.
- Big meetings, but also chance to be involved individually.
- Co-production. Service users and carers involved in all decisions at all levels.
- Provide advocacy to support people's involvement.
- People should be able to share their stories – and for these to be listened to.
- NHS England / CCGs should pay local groups to involve people – including seldom heard groups.

What should your local care partnership report on?

- It is vital to meet people and hear real stories - not just case studies chosen by the local area.
- There needs to be clear information on what commissioners are commissioning. There should also be robust data on the local population. These statistics must be correct, accurate and transparent.
- People said that there should be reporting on quality of life and outcomes.
- People must have a chance to be involved in the decisions, locally. There should be information about how work is progressing.

2.3 What will we do now?

- Transforming care partnerships are now formed and will be working towards a draft a plan by 8 February 2016. The plan will be finalised by 11 April 2016.
- Areas will then work to implement these plans. Listening to and involving people throughout this time will be vital.

3 What does good easy read look like?

3.1 What did we tell you?

We told you about the Accessible Information Standard. We told you that it is law for organisations that provide NHS services or adult social care to follow the Accessible Information Standard by July 2016. It means that organisations have to make information accessible to patients and service users. This includes making sure that people get information in different formats if they need it – for example braille, large print or easy read.

We told you that NHS England needs to communicate with you in a way that you understand. We need to know from you, what makes good easy read?

3.2 What did you tell us?

We asked you three questions about your experience of easy read. This is how you replied:

1. Do you use easy read
    - Always – 28%
    - Sometimes – 44%
    - Never – 28%

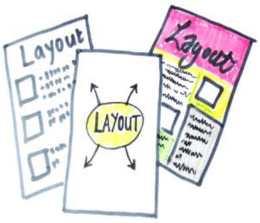
2. Do you get accessible information from your doctor?
    - Always – 9%
    - Sometimes – 18%
    - Never – 73%

3. Would easy read help you make decisions?
    - Always – 48%
    - Sometimes -24%
    - Never – 28%

We asked you to tell us about what you think makes good easy read. Here are the main messages you told us:

What should be in easy read?

- Anything written about ‘me’
- Documents to help me have control of my health
- Documents asking for my opinions or my vote
- This tells us that people want easy read to help them have more power.



Layout (how the information is presented)

- There is already a guide about what easy read should look like. People agreed that this works.
- People prefer documents with pictures on the left and words on the right.
- People would like to choose for themselves how documents look (-but it is hard to make documents that can be changed).

Pictures

- A lot of people said they prefer photos. Some people prefer good quality drawings.
- Pictures and words must match.
- Pictures must be used consistently. This means for example, the picture for ‘Steven’ must be the same picture throughout a document.

Content (how much information)

- Some people said everything should be made just in easy read. Some people said there should be easy read sections in the main document. And some people said there should be a separate easy read version of documents.
- Some people said there should be a short, easy read introduction giving the main messages of the document.

Involving people in making easy read

- Remember that it takes time to make good easy read!
- People should be involved in making and testing easy read.
- People should be paid for their work making easy read.

Other ideas about easy read

- The easy read version must be published at the same time as the original document.
- Documents should have small file sizes so they can be emailed.
- Remember that easy read is only part of making things accessible – services must do all the other things too!

3.3 What will we do now?

- We are going to make a guide about easy read. It will be called ‘What makes easy read good for NHS England’. It will be made up of your comments and feedback about what good easy read looks like.

- We will also ask for feedback online and in focus groups so that people who were not at our event can give us their ideas.

- We will make a checklist that easy read quality checkers in NHS England can use. It will help make sure the easy read NHS England publishes is of good quality.

- Most people in the workshop said they ‘sometimes’ or ‘never’ use easy read. We will look at other methods of communicating information to you that is not in easy read.

4 How NHS England shares information with you

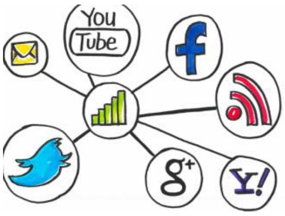
4.1 What we told you

We told you that NHS England shares information in lots of different ways - on the website, on social media, through emails and newsletters and at events. We know there is sometimes poor communication from NHS England. We want you to tell us what you think about our current methods of communication and how you would like to receive information from NHS England in the future.

4.2 What you told us

NHS England Website

- It would make things easier if there were separate pages for (1) learning disability and (2) autism. Each page should have a list of relevant documents.
- At the moment the website is not very interesting - it needs to be simple, attractive and in colour. Perhaps there could be more audio and video.
- The website should link to other relevant websites.



Social Media

- Most people found out about our Forum event through their own networks on Facebook. NHS England needs to make friends with more groups on Facebook and use the well-connected networks to promote the Forum.
- We should be using other methods of social media like blogs, videos and LinkedIn.

Newsletter and Update Emails

- There could be two newsletters: one for carers and one for people with a learning disability.
- In British Sign Language the sign for ‘Engage’ is an Engagement Ring – it is not a good name for the newsletter.
- Articles in the carers’ newsletter need to be positive and about reality and resilience.
- Members of the Forum would like to be involved in designing, writing and editing the newsletter.

Other - Future events

- Future events could be live streamed or recorded so that people who cannot get to the event know what happened.
- You could invite people from the Forum (experts by experience, family members and carers) to event planning meetings.

4.3 What will we do now?

- We have started making some changes to our website, based on your comments. You can look at the learning disability page of the NHS England website here.

- We are going to find alternative ways of giving you information that is not in easy read. We will start posting short videos containing information that we think might be useful to you.

- We are planning an easy read newsletter for people with a learning disability and/or autism.

- We want to give grants to organisations to help them talk to people with a learning disability. The grants will be given to help us hear ideas and concerns from people who might not come to meetings. We will give you more information about how you can apply for a grant in the New Year.

- We always welcome feedback from you about how we communicate.

5 What should NHS England's Priorities be?

5.1 What we told you

We told you about the five priority areas NHS England is currently working on to do with the health of people with a learning disability. They are:

1. Health inequalities
2. Access to cancer screening
3. Access to healthcare
4. Early death
5. Annual health checks

We asked to hear your thoughts on each of NHS England's priority areas. We also asked what you think NHS England should be focusing on, to improve people's health the most.

5.2 What you told us

These are some of the main ideas you talked in the priorities workshop:

Your Priorities

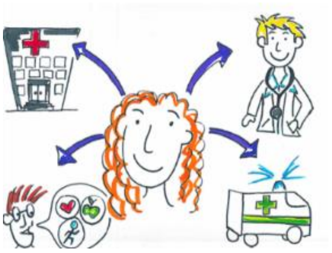
- More consistent care for people with a learning disability and/or autism including eye tests and dentistry.
- Doctors and nurses need educating and empowering to work with people with a learning disability and/or autism. They need to recognise distress and anxiety and what they can do to help.

Health Inequalities

- Health inequalities of people with a learning disability and or autism are made worse by other things that go on in society – bad housing/poor education/run down communities.
- We should not make assumptions about what people with a learning disability need. We need to ask them and those closest to them.

Access to cancer screening

- More information is needed about cancer – lots of people are not being screened and do not know the symptoms of cancer.
- It is important not to assume anything (for example that people with a learning disability are not sexually active and therefore do not need information on or testing for cervical cancer).



Access to Healthcare

- Some people who live independently do not have enough support to fully access or understand their healthcare. There needs to be better information (which is accessible and jargon free) about ‘my care’ and ‘services that are available to me’.
- There needs to be better communication with carers in order to help people with autism / a learning disability access services.
- Paramedics need training in autism.

Annual Health Checks

- People are not always being contacted about their Annual Health Checks. There needs to be more communication from health services.
- Annual Health Checks are important because they are about prevention. They will improve other issues automatically. It would be a good idea to talk about healthy eating and exercise too.

Early Death

- There needs to be more research done into the reasons why people with a learning disability die prematurely. There is not enough understanding and we should not assume the reasons people die early.

5.3 What will we do now?

- We will work closely with the National Mortality Review .
- We are working with Clinical Commissioning Groups (CCGs) to increase the numbers of annual health checks. We are working to make sure health checks are high quality and lead to a good Health Action Plan.
- We are working towards getting a ‘flag’ on health records systems. This will mean that health services will know that someone has a learning disability and what support could help them before an appointment.
- We hope to find resources to work on autism as well. We will tell you as soon as we find out.

6 Your feedback

Thank you for your feedback about this event. The main messages we heard were:

Positive comments

- Enjoyable and informative event
- Loved that the event was organised with people who have a learning disability
- Graphic facilitation was ace!
- The meeting was a good start
- The interview element of the presentation was a refreshing way of doing things
- There were good handouts, clear and good use of easy read
- The table discussions and interactive element were great
- The staff were amazing and I feel they listened

Comments about how to improve

- It would be good to see more publicity, particularly with learning disability communities so that people with a learning disability are aware that there is an opportunity to get involved in health and social care.
- There should be proper feedback forms with clear questions.
- You should think about having proper table facilitators.
- It was hard to listen in such a big room with lots of conversations.
- Do not lose track of the events aims - ‘Autism’ fell off the agenda, excluding people with autism.
- The aims of the day and what we want to get out of the event should be clearer.
- It was good but not what I was expecting – I came to talk about how to get people out of Assessment and Treatment Units.

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If you would like this report in an alternative format (for example large print, braille or audio), please contact us.