

NHS Long Term Plan Event

Learning Disability and Autism Focus Group, 2nd May 2019



Shaping the future of our NHS in Harrow

“Medical professionals are informed, and we trust that they know what they are talking about.”

Harrow resident and service user

What is the NHS Long Term Plan?

With growing pressure on the NHS - people living longer, more people living with long-term conditions, lifestyle choices affecting people's health - changes are needed to make sure everybody gets the support they need.

The Government is investing an extra £20 billion a year in the NHS. The NHS has produced a 'Long Term Plan' setting out the things it wants health services to do better for people across the country.

This includes making it easier to access support closer to home and via technology, doing more to help people stay well, and providing better support for people with long-term health conditions.

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Whilst the national plan has set some clear goals, it's up to local areas to decide how they're achieved - that means engaging with local people and listening to their experiences and expectations of current and future services.

Healthwatch Harrow, alongside the network of 152 Healthwatch organisations has collected local views on the Long Term Plan through surveys, focus groups and events between April and May 2019, to give tens of thousands of people the opportunity to help local hospitals, GP surgeries and community services hear about the changes people would like to see.

On Thursday 2nd May, we engaged with 11 local residents with a Learning Disability or Autism. Attendees were aged between 20 - 50 years, and of various ethnicities including White British, Mixed Black African and Mixed Asian.

Experience of Services

At table discussions, we asked people 'what works, what doesn't work, and what could easily be improved'?

What Matters

We then asked people what matters most to them and recorded experiences around prevention and early intervention, assessment, diagnosis and treatment, and ongoing care and support.

Communication

We also asked people how communication and engagement across services could be improved.

This report records their views.

1. What works well, and what could work better?

Generally we asked people what they feel works well and what could work better.

1.1 What works well?

Health Passports are considered a 'good idea' - but only if they are actually utilised by staff:

"Health Passports - when a person has them and the medical professional uses them."

Levels of expertise and knowledge are also particularly appreciated:

"Doctors - knowledgeable, helpful and we trust them."

"Medical professionals are informed, and we trust that they know what they are talking about."

"Dentists - advising what is wrong with your teeth."

The following comments were also made:

"Learning Disability Nurses in hospitals."

"Easy to get appointments."

"Signing in technology at appointments is accessible."

1.2 What could work better?

Some people experience exclusion or poor treatment and support.

"Where medical professionals talk to the parent / carer rather than the person with a learning disability."

"Not being responsive to people's needs and ignoring people with a disability."

"Receptionists should be more sensitive on the phone and have a better understanding of learning disability."

The importance of clear, accessible and effective communication was also noted:

"Information and forms not always provided in an accessible way - complex language used."

"Where English is not the first language of the doctor, it is sometimes difficult to be understood."

"There isn't always good communication between staff and patients."

The following comments were also made:

"Appointments always running late - you can be waiting for a long time."

"Northwick Park Hospital - out dated and not very welcoming."

"Reasonable adjustments not always made (double appointments not offered)."

"Health Passports aren't always recognised or used by some medical professionals."

2. What could easily be improved?

We asked people to consider what could be improved 'easily'.

2.1 What could easily be improved?

People made comments about training, awareness, communication and resources:

"All medical professionals to be aware of Health passports and know to use them."

"Information and forms being provided in easy read. Removing complex language."

"Some way of people knowing that you have a learning disability, so they know to make offer reasonable adjustments such as double appointments at the doctors."

"More online access to doctors to get advice."

"Medical Professionals and staff receiving more training about learning disability."

"Learning disability nurses having more time / resource so they are not spread too thin."

3. Experiences - From Prevention to Ongoing Care

We talked about various aspects around prevention and early intervention, assessment, diagnosis and treatment, and ongoing care and support.

3.1 What matters to you, what were your experiences?

Prevention and/or early intervention

Was not considered 'particularly relevant' to learning disability as it is a life long condition. But for other conditions prevention and early intervention was seen as very important.

Assessment, diagnosis and treatment

The group felt that assessment, diagnosis and treatment at the right time is very important.

Ongoing care and support

Again, the group regarded this as very important.

Continuity (choice of professional)

The group agreed that it was more important to see a medical person who was qualified who was free immediately if it was urgent.

It did help to see someone who knew you if it was less urgent. It helps if someone knows you and your history.

3.1 What matters to you, what were your experiences? (continued)

How could communication and engagement be improved?

It should be more accessible using straight forward language. It is better to do this as a group, but happy to receive letters.

The survey should have been provided in an easy read format.

4. Health and Wellbeing

We also asked people what they do to stay healthy, how they know that they are healthy, and what they do when not feeling well.

4.1 What do you do to stay healthy?

People cited the following:

- Gym
- Eat fruit
- Football
- Physical work
- Keep fit classes
- Think about what you eat and drink
- Dancing
- Moving around
- Walking
- Cricket
- Personal trainer

4.2 How do you know you are healthy?

People cited the following:

- Doctor
- Blood tests
- Blood pressure
- Balance of eating and bowel movements
- Getting tired
- Headaches

9.3 What do you do when you don't feel well?

People cited the following:

- Talk to your family or a friend
- U Tube
- Visit doctor
- Take painkillers
- Rest
- Visit pharmacy

Distribution and Comment

This report is available to the general public, and is shared with our statutory and community partners.

If you have any comments on this report or wish to share your views and experiences, please contact us.

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