

# NHS Long Term Plan Engagement

A focus on Learning Disabilities



Shaping the future of our NHS in Central and North West London

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

Local resident and service user

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## **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.

## **Engaging Local People**

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 organisations in Central and West London, alongside the national Healthwatch network has collected local views on the Long Term Plan through surveys, focus groups and events between April and June 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.

In this report, we look at experiences and expectations associated with Learning Disabilities.

# What matters most to people in Central and North West London?

Engaging with 75 people - service users, families and carers we found that:

## Learning Disability Services

### GP Services

When talking about local GP services, people comment on feeling excluded or ignored, and not being able to understand written or spoken information. It was suggested that increased training and awareness could do much to address this.

Some people also felt that levels of support could be greater, for example longer appointments and shorter waiting times for people with a learning disability. It was suggested that the system could 'flag' disabilities so staff know when to make reasonable adjustments.

### Hospital Clinics and Services

We heard accounts of good levels of involvement, communication and support from hospital doctors, nurses and other staff. Levels of expertise and knowledge are also particularly appreciated.

However, lengthy waits can be uncomfortable and problematic for patients, families and carers. It was suggested that use of Health Passports could help staff to prioritise. Some patients would also like more information in easy read.

People were appreciative of specialist nurses and doctors, but question staffing levels (one particular nurse has a catchment of three major hospitals).

## Learning from Discussion (Checklist)

### GPs, Hospitals and Clinics - local people would like:

- Recognition of their disability or condition.
- To be included, involved and respected.
- Good levels of awareness (training for staff).
- Clear written and oral language and effective communication.
- A level of support that reflects their condition or need.
- Well resourced specialist nurses and doctors.
- Awareness and active use of Health Passports.

## From Diagnosis to Ongoing Care

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

### Assessment, Diagnosis and Treatment

People felt that assessment, diagnosis and treatment at the right time is very important. Most people agreed that it was more important to see a medical person who was qualified who was free immediately if it was urgent. However, if less urgent it helps if 'someone knows you and your history'.

### Ongoing Care and Support

We heard accounts of good levels of support and communication. When asking what could work better, people are quick to comment on long waiting lists and lack of support overall. Some people suggested more emotional support for patients and carers, plus practical assistance (such as help to fill in a form).

We also asked people to consider what could be 'easily' improved. Suggestions included enhanced training and awareness, and clearer communication to patients, and professionals.

## Learning from Discussion (Checklist)

### Assessment, Diagnosis and Treatment - local people would like:

- Timely diagnosis and treatment.
- Continuity (choice of professional) if required.
- Timely access to specialists and support.
- Emotional and practical support for patients and carers.
- Good levels of awareness - training for staff and education for the general public.
- Clear communication, including professional-to-professional.

## What did people tell Healthwatch?

Here, we take a more detailed look at the top themes emerging from discussion. Generally we asked people what they feel works well, what could work better, and what in their view could be improved 'easily'.

### 1. GP Services

This section explores top themes around GP services.

## 1.1 What works well?

People were complimentary about automated signing-in systems, choice of appointment times and in one case, accessible information.

### GPs: What works well?

#### Selected comments:

*"Signing in technology at appointments is accessible." [Harrow]*

*"I can go to the GP in the morning, afternoon or evening - that's a good thing."*

*"Doctor provides easy read (a carer)." [Brent]*

*"I have a good relationship with my GP and am involved in my treatment plan, though I accept that is 'quite rare'." [Hounslow]*

## 1.2 What could work better?

People comment on feeling excluded or ignored, and not being able to understand written or spoken information. It was suggested that increased training and awareness could do much to address this. Some people also felt that levels of support could be greater, for example longer appointments and shorter waiting times for people with a learning disability.

### GPs: What could work better?

#### Selected comments:

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

*"Received a text and didn't understand the message, patient thought they would have to pay if they miss the appointment." [Brent]*

*"Information and forms not always provided in an accessible way - complex language (jargon) used." [Harrow]*

*"One person said that when he asked his doctor for more information on his medication, the doctor refused to sit down and explain as he was too busy." [Hounslow]*

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

*"Reasonable adjustments not always made (double appointments not offered)." [Harrow]*

*"Patients with learning disabilities need more support and less medication."*



[Brent]

*"Appointments don't run on time - get anxious while waiting - don't get given an update on how long the delay will be." [Brent]*

*"Can't book appointments to be seen on the same day." [Brent]*

### 1.3 What could easily be improved?

People want clearer written and oral communication and some cited greater levels of training and awareness. It was felt that the system could 'flag' disabilities so staff know when to make reasonable adjustments (such as shorter waiting times or double appointments).

#### GPs: What could easily be improved?

##### Selected comments:

*"Information and forms being provided in easy read. Removing complex language and acknowledging the Accessibly Information Standard." [Harrow]*

*"GP's to break down the information and ensure it has been understood." [Brent]*

*"Medical professionals and staff receiving more training about learning disability." [Harrow]*

*"Inform patients if there is a delay and ensure people with learning difficulties have understood." [Brent]*

*"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." [Harrow]*

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

## 2. Hospitals and Clinics

This section explores top themes around hospitals and clinics.

### 2.1 What works well?

We heard accounts of good levels of involvement, communication and support from hospital doctors, nurses and other staff. Levels of expertise and knowledge are also particularly appreciated.

People were appreciative of specialist nurses and doctors, but question staffing levels (one particular nurse has a catchment of three major hospitals).

### Hospitals and Clinics: What works well?

#### Selected comments:

*"Good explanation while being treated." [Brent]*

*"Assistance from the nurses and staff is good." [Brent]*

*"There is a learning difficulties nurse that helps and supports patients - although one nurse for 3 hospitals - NPH, CMH and Ealing." [Brent]*

*"Staff listened to what the patients had to say and were patient." [Brent]*

*"Doctors - knowledgeable, helpful and we trust them." [Harrow]*

## 2.2 What could work better?

Lengthy waits can be uncomfortable and problematic for patients, families and carers. Some patients would also like more information in easy read.

### Hospitals and Clinics: What could work better?

#### Selected comments:

*"A family member had to go A&E and waited for 5 hours. It was stressful, and no one gave any update to when we'd be seen." [Brent]*

*"There should be no waiting time for patients if they have Autism. Carers find it very stressful to manage the patient when they become restless and start to get aggressive or anxious and worried." [Brent]*

*"Two cases where people had to wait 24 hours to be seen in A&E, and another had to wait 8 hours." [Hounslow]*

*"Not enough information available in easy read." [Harrow]*

*"Health Passports aren't always recognised or used by some medical professionals." [Harrow]*

*"Concerned about patient confidentiality - their hospital passport is on display at the end of their beds and "nosey patients" might see them." [Hounslow]*

### 2.3 What could easily be improved?

People felt that greater levels of training and awareness would enhance support, including while waiting. Active use of Health Passports could help staff to prioritise.

#### Hospitals and Clinics: What could easily be improved?

##### Selected comments:

*"Take into consideration if a patient with autism is being restless and may need to be seen before other patients." [Brent]*

*"All staff need to have awareness on Autism and best way to manage and help patients." [Brent]*

*"All medical professionals to be aware of Health passports and know to use them." [Harrow]*

*"Difficult to remember where the hospital is or how to get there. May need a map printed out for them with directions." [Brent]*

*"West Middlesex Hospital should adopt a 'numbers system' for queuing." [Hounslow]*

## From Diagnosis to Ongoing Care

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

### 3. Assessment, Diagnosis and Treatment

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

Most people agreed that it was more important to see a medical person who was qualified who was free immediately if it was urgent. However, if less urgent it 'helps if someone knows you and your history'.

### 4. Ongoing Care and Support

We heard accounts of good levels of support and communication. When asking what could work better, people are quick to comment on long waiting lists and lack of support overall. Some people suggested more emotional support for patients and carers, plus practical assistance (such as help to fill in a form).

We also asked people to consider what could be 'easily' improved. Suggestions included enhanced training and awareness, and clearer communication to patients, and professionals.

#### 4.1 What works well?

We heard accounts of good levels of support and communication.

##### Ongoing Care and Support: What works well?

###### Selected comments:

*"Support from nurses and carers." [Brent]*

*"When appointment details are written down and explained." [Brent]*

*"Support to stay stable and mind positive." [Brent]*

*"Receive support for medication." [Brent]*

#### 4.2 What could work better?

When asking what could work better, people are quick to comment on long waiting lists and lack of support overall. Some people suggested more emotional support for patients and carers, plus practical assistance (such as help to fill in a form).

##### Ongoing Care and Support: What could work better?

###### Selected comments:

*"Not enough support especially from mental health specialist." [Brent]*

*"Long waits to get support from a specialist." [Brent]*

*"Whilst they appreciate the support of their learning disabilities group, the staff do not always take the time to understand service user's individual needs. For example, one of the service users who is blind was not allowed on a trip and another with lymph edema was not given adequate physical support on an outing." [Hounslow]*

*"Not able to get appointments to see specialists, such as psychiatrists." [Brent]*

*"Some can't fill in forms and there is not always support available to help." [Brent]*

*"More emotional support for carers and those living with learning difficulties." [Brent]*

*"Do not understand information they receive from the NHS." [Brent]*

*"GPs and nurses do not understand learning difficulties needs." [Brent]*

*"The group agreed that they would like to receive home visits from district nurses after discharge." [Hounslow]*

### 4.3 What could easily be improved?

We also asked people to consider what could be 'easily' improved. Suggestions included enhanced training and awareness, and clearer communication to patients, and professionals.

#### Ongoing Care and Support: What could easily be improved?

##### Selected comments:

*"Extra training for nurses on how to deal with learning disability issues." [Harrow]*

*"Educating the users of on-going services about learning difficulties." [Brent]*

*"Less jargon from professionals and communication between carers and health professionals in simple English." [Brent]*

*"Not all disabilities are visible, but should all get equal care." [Brent]*

*"They would like their names called instead of being displayed in the banner." [Brent]*

*"Better if the appointment were running on time." [Brent]*

*"Being able to choose the gender of your doctor and option of treatment locally." [Hounslow]*

### Acknowledgements

This project was undertaken by the following Healthwatch organisations:



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## Distribution and Comment


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

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

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They should have a better understanding of learning disabilities.”

Local resident and service user