**Disability North West Forum – Listening to our communities’ event (27/06/2023)**

**Participants**

The group consisted of nine members of the disability forum, with two BSL signers, and ICB C&E team members – David Rogers, Lucy Atkinson, Jeremy Scholey, and Chantelle Bennett.

**Background**

Following the formation of Lancashire and South Cumbria ICB, we have been keen to progress the statutory duty to involve the public by developing a programme of listening events covering Lancashire and South Cumbria. This forms part of our process to reach out, listen to and involve our communities. The event at the Disability North West forum was arranged to engage with an existing group that may rarely have been included in previous engagement exercises but whose voice needs to be heard in the same way as others we listen to and engage with.

The session was given over entirely to listening to what attendees had to say about their experiences of health services in the area; what was working well, what isn’t working well, and what this means for people with disabilities.

**Feedback**

The services or issues listed below are taken from the group as a whole and based on the lived experience of those within the group. Some of the points made can be applied more generally across Lancashire and South Cumbria. We are building a powerful bank of insight about what matters to people with a disability in Lancashire and South Cumbria. We will add these insights to those we have gathered from people with disabilities or sensory impairments in other listening events to create a compilation of common insights and experiences for the system. However, this brief report is for the Disability North West forum to contribute towards improvements as well as an ongoing dialogue about what is important to people with disabilities.

The following section is broken down into sections according to the topics raised, discussion points, key issues, and finally some action or learning points. The section on action and learning points is purposely left blank at this stage to allow for others to contribute to this report. Firstly, we will share the draft with the group, and then we will share this with key NHS leaders and their teams to see what we can in response to the key issues.

**GP services/Primary Care**

**Discussion:**

**GP appointments** – You have to be on the phone at 8 o’clock to try and get an appointment, but this is very difficult for many people, especially for people with disabilities. Some GPs use the NHS App to book appointments but there are never any appointments available via the App.

Where someone can’t navigate the system due to their disability, they physically have to go to the GP surgery to get an appointment but even getting past the receptionist can be very difficult. Receptionists now do triage, but this is making it worse. It’s not their fault, they are doing what they have been asked to do.

You can’t get through to the GP to have information, like a consultant letter, explained to you. Written materials often use inaccessible language, with too much jargon and fonts that are too small for people with visual impairments, dyslexia or other learning difficulties to read or understand. There is too much paperwork for people who struggle to read/process information.

We need a glossary of NHS jargon so that patients can understand what they are being told – probably should be shared with consultants too.

**Technology and systems** – Accessibility on GP practice websites is often poor. They do not use the accessibility toolbar and screen readers that will help people with sensory and other disabilities navigate their websites. The technology to use voiceovers, subtitles and BSL signing is available, but this is not used.

Everything is now on an app. The apps are very difficult for some people to use – people with visual impairments, learning disabilities and others, who will miss appointments and other valuable information because of this. The apps often require you to put in information like date of birth or NHS number, and for visually impaired people this is very difficult to do. There should be a choice about how information is shared and received.

Information screens in GP surgeries usually have the sound turned off. This is no use to people with visual impairments – it isn’t very useful for hearing people either. When tackled, staff say they have heard it all before and turn the sound off. This makes us feel as if we don’t count. They don’t often use subtitles either, so will also be of little benefit to people with hearing impairments.

Technology is the nemesis of some people, not the solution. Lots of people prefer in person contact/appointments. They can’t follow or understand what is written on a screen/leaflet and so may not be able to follow medication instructions or give medical staff the correct information. This lack of understanding can have a huge impact on a disabled person’s health.

**GP/Primary Care services** – GPs often direct people to walk-in or urgent care centres – in Fylde they will direct you to White Gates Drive. This means two or three bus journeys to get there. This is very difficult for visual impaired people and people with other disabilities. What about those people who cannot afford public transport or can’t use it due to their disability?

There should be an urgent care centre in Fylde.

GP surgeries can use flags in their records to identify patients with disabilities. Some use these flags, but many do not. Where they are used there is no reason for GP staff not to be aware that someone is visually impaired or has any other type of disability. Flags on records should be used and staff should take notice of them.

GPs do not seem to know about misophonia (sensitivity to certain sounds), which can cause behavioural difficulties; this is becoming more common now and GPs should have more knowledge and understanding of this issue.

GPs can refer to social prescribers, but patients don’t know anything about them. They should be promoted more so patients know they are available.

Only priority cases get access to chiropody services; they should be available to others too.

A good GP shows courtesy, respect and politeness. Some GPs do not do this and just look down their nose at us.

**Pharmacies** – Pre-payment prescription scheme for medication makes it more affordable. Some pharmacists can now provide lower-level medications without needing to be prescribed by GPs first. There is also good advice available from pharmacists, but this is not widely known.

**Dentistry** – There are no NHS dentists in Kirkham – they are all private. The NHS dentists in Preston have no vacancies on their lists; only emergency care is available.

**Key issues**:

* GP appointments remain difficult to access with long waiting times
* Technology helps some patients, but it isn’t good for everyone; it can make it more difficult for patients with visual or hearing impairments or people with learning difficulties – there should be a choice about how information is given
* Where technology is used it should be used properly – sound turned on; subtitles used etc. otherwise they become a barrier to access or cause frustration for people with sensory impairments and even for people without impairments
* Receptionists are now often doing triage, but this can make it worse to access services
* Flags on records should be used both to identify people with disabilities and specific needs, and by staff to understand the patients they are dealing with
* Written material is too full of jargon, difficult to understand and often not accessible to people with sensory impairments or learning difficulties (applies equally to secondary care/hospital services)
* Should produce a jargon-busting book for patients (and consultants)
* Referrals to urgent care centres or hospitals are done without any thought about how people with disabilities will get there
* A range of services are very restricted or not promoted enough to patients

**Action/learning points**:

**Hospital care**

**Discussion:**

In audiology clinics staff still come out and shout the name of the next patient, even though they know almost everyone there will have hearing loss. There are no signs or visual displays used.

Visually impaired patients have similar problems at outpatients and other clinics. Staff will point in the direction of the clinic, but visually impaired people can’t see this. Outpatients will have a ticket system, with a display of the ticket number on the wall. Nothing is said, there is no “would ticket number….go to” to accompany the visual display, so people with visual impairments are not catered for.

Often need to wait to be seen a long time after the appointment time. Sometimes waiting for hours in outpatients. Why can’t we be seen at the appointment time, or at least kept informed about delays? This can be hard for people with learning disabilities/autism, to wait without knowing what is going on. This causes anxiety.

Alison Cookson has a ‘Your care is our business’ video for LTH, which helps with understanding who everyone is and where things are in the hospital. This is really helpful and could be done in other locations.

People First do training with hospital students to teach them about treating people with learning disabilities. This gives them different scenarios and takes them through issues like leaving hospital at 5am. Learning disability training is mandatory. Training about the challenges facing people with sensory impairments is not mandatory. Why not?

The Patient Experience/Engagement teams in the hospital trusts work hard but we don’t know what they do.

Hospital discharge often means people are given an information overload. Staff give a lot of information about medications, follow-up appointments and conditions management that people struggle to take in. This is worse for people with sensory impairments or learning difficulties/dyslexia, who may not be able to read or understand the information being given because of the jargon, language used, size of the print or the format used.

**New Hospitals Programme (NHP)/clinical strategy** – There is some good information about the NHP available, but there is also some misinformation in the newspapers, which stirs up people’s anxiety.

There is news circulating that the new hospital will be outside Preston. How will this impact on the elderly, people with visual impairments, people with learning disabilities? How will this impact on waiting lists and on the staff working in the hospital, and on the ambulance service?

Wherever you put the new hospital you must have good transport to get there, both for patients and staff. To get to Royal Preston Hospital now takes two bus journeys. If the clinic is at 6pm you can’t get home using public transport. This is very difficult for people with visual impairments and for people with other disabilities, for people who can’t drive or don’t have access to a car. If the hospital is moved outside Preston this will be even worse.

Going to health appointments can be a whole day out for disabled people using public transport, as the links are not always reliable. If people can’t get to the hospital (or GP), how do they access the service?

What happens to the current Royal Preston hospital? Will that still be used when the new hospital is built?

It would be good if the new hospitals programme people came out and did events like this.

**Key issues**:

* No thought is given to how people with sensory or learning disabilities are given information at clinics/appointments, even in services where the disability is the reason for their attendance
* Appointment waiting times are too long and can cause anxiety for some patients
* Discharge information can be overwhelming and inaccessible for people with sensory impairments and learning disabilities
* ‘Your care is our business’ video should be more widely shared across trusts
* Building the new hospital out of Preston will have significant implications for how people with sensory impairments and many others are able to access hospital services and clinics
* Transport is a key feature of supporting access to hospital services and must be part of any plans
* Thought needs to be given to how people who cannot get to a hospital receive the service

**Action/learning points**:

**Staff in general**

**Discussions:**

Why are NHS staff not routinely trained in British Sign Language (BSL)? There are also many deaf/hearing impaired people who do not use BSL; they lip read. There is only provision for BSL interpreters. Staff do not ask what a person needs – they make assumptions based on appearances.

We are worried by the doctors’ strike but not angry with the young doctors. They should get what they are owed. There are 100,000 vacancies in the NHS – it would get more staff if they were paid properly. Staff shortages has a knock-on effect on waiting lists and treatments, and on having appointments on time.

We need to revisit a more caring approach. It feels as if we are on a conveyor belt – come in, get treated, go home. There is no consideration of the individual. A holistic approach is needed. Staff should look at the person as an individual and not just at their condition.

There isn’t the quality and quantity of staff needed. A nurse used to escort a mother and baby to the car and see them off – now they are just sent on their way from the ward. It’s not the same level of care. What does caring entail now? What do NHS staff understand as ‘care’?

A few personal experiences were shared which give examples:

* patient was on a ward when the heart monitor alarm went off in the next bed during the staff handover. The alarm was ignored, and it took over 10 minutes to get to the patient, who had a cardiac arrest and died.
* Visually impaired patient was given information which they could not see well enough to read due to their sight impairment and was told to ‘try harder’ by the nurse.

There are a lot of agency staff being used, who seem to be there for the money. There are not enough managers on the night shift, with no-one to oversee the care that is given.

The communication techniques staff use is important. The way questions are asked makes a huge difference to the answers patients give.

Do staff understand that not everyone can communicate easily? Autistic people may struggle to process and answer questions. Staff do not have a good understanding of autism. Staff should offer guidance rather than tell them what to do.

Staff avoid speaking to people with learning difficulties. They speak to the support worker/carer instead and assume the patient won’t understand. This is very frustrating and dehumanising.

People with certain disabilities need reassurance during things like vaccinations, injections or blood tests.

Staff should never rely on friends/family to read letters/interpret for patients, as this can be a gross invasion of privacy. The information they provide should be accessible to the person they are intended for.

Many of these issues or concerns have been told to the NHS before. Each time it is told people may relive the trauma. This can be draining. What happens to the masses of information and feedback given by VCFSE groups to the NHS?

When asked why it was that little progress was made, attendees felt this was down to the attitude of the NHS and barriers at the top. Much of this was down to staff training.

**Key issues:**

* Staff need better training in caring for patients with sensory impairments, including BSL and other communication techniques
* Staff should be paid the money they feel they are entitled to – this will impact on recruitment and retention of staff and help fill the many vacancies in the health service, with less reliance on agency staff
* A more caring, holistic approach to care needs reintroducing – patients tend to feel they are on a conveyor belt
* Staff need greater understanding of autism and should engage with these patients directly
* Staff should never rely on friends/family reading correspondence/information for patients – it should always be in the format required by the patient
* The NHS needs to adopt a fresh attitude to how it deals with patients with sensory impairments and other disabilities if further progress is ever to be made

**Action/learning points**:

**Some further positive experiences**

**Discussions:**

The listening events have been good – we do actually feel as though we are being listened to.

We do get a good service from a lot of the NHS. We don’t say enough about what is good. We need to tell the NHS when they are doing well and not just when they are doing badly.

Very positive experiences of the NHS when a baby and the NHS saves lots of lives in emergency situations.

Could not afford to be a diabetic in any other country. All the medication needed is provided me.

Appreciate that the NHS is free at the point of use.

Very lucky to have centres of clinical excellence – stroke, cardiac services, trauma, eye health.

Really liked mobile services during COVID e.g. vaccination clinics on buses in supermarket car parks, which were very accessible. This takes services to the people who need them. We should do more of this.

A Visual Impairment Passport has been introduced at University Hospitals of Morecambe Bay, which can help support appointments at the hospital.

Like it when health programmes are at places like football stadiums – these are easy to get to and we might be going there anyway for a sports event.

**Key issues:**

* We need to say more about the good things within the NHS
* We have a lot to be grateful for in the NHS – centres of excellence, access to medication and diabetic services
* More consideration to mobile services – taking services to the people
* Wider promotion of the Visual Impairment Passport

**Action/learning points:**