

NHS Long Term Plan

A report of evidence base collected by Healthwatch
Enfield

wh  **t**

would you do?

It's your NHS. Have your say.

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Introductions

During April and May 2019 Healthwatch Enfield engaged 426 local residents in conversations about the NHS Long Term Plan using:

- Healthwatch England survey (general) collecting 6 responses
- Healthwatch England survey (conditions) collecting 5 responses
- North London Healthwatch survey collecting 250 responses
- Focus groups attended by 25 participants and supporting community outreach where feedback was gathered from 140 local people

North London Healthwatch Long-Term Plan Survey

During May 2019 Healthwatch Enfield engaged with 250 Enfield residents about the NHS Long-Term plan via a survey developed by NCL Healthwatch.

If you were in charge of planning how the NHS spends its money, what three areas would you focus on and why?

According to feedback gathered by Healthwatch Enfield from 250 local people, the three areas that should be prioritised when developing NHS services of the future are:

- improving access to services (indicated by 33% of respondents)
- improving care for those most vulnerable who may need it the most (indicated by 25% of respondents) with particular focus on developing:
 - Cancer care
 - Dementia care
 - End of life care
 - Care for long term conditions
 - Paediatric care
 - Young people’s mental health services
 - Mental health services
 - Maternity services
- reviewing where the NHS spends its money and how efficient this is (indicated by 25% of respondents)

To **improve access to services**, Enfield residents, who engaged in conversations, would invest money in primary, community and secondary care.

‘Reducing waiting times to see a G.P. as they are the gateway to hospital services.’

‘We are supposed to have community support I don’t think it happens’

‘Have more A&E departments, have more beds in hospitals and invest into reducing waiting times.’

To secure the ability for the NHS to offer more appointments and cut down waiting times, investment needs to be made to recruit more staff. This was closely followed by the need to review processes, developing technological solutions and ensuring research is at the forefront of spending so that local people receive the highest quality of care.

‘More money for GP surgeries to enable them to provide more staff, both doctors and qualified nurses, to manage the needs of their patients’

‘Buy from where you can access cheaper not just specific places instructed by NHS this wastes money’

‘Reviewing operational processes so that NHS can stop wasting money. For example, why send letters when the same information can be communicated via e-mail?’

‘Focus on technology for streaming appointments etc.’

‘Research into cures for life-threatening chronic illnesses like diabetes, cancer, Alzheimer’s as these are what people are most scared of.’

‘More staff in every area of the NHS so that hospitals/doctors/nurses/specialists have more resources and patients have shorter waiting times for these services’

Top areas of priority for the future of the NHS

With the NHS Long Term Plan outlining developments within fifteen different areas, from support in care homes to improving care for people with cancer, evidence base collected by Healthwatch Enfield indicates which services should be prioritised by North London Partners in Health and Care:

Using NHS funding more effectively	45%
Making sure that everyone gets the same care, regardless of where they live	39%
Having more staff	38%
Reducing the pressure on A&E departments	38%
Having access to services near me, outside of the hospital	37%
Improved services for children and young people, to give them a strong start in life	34%
Having shorter waiting times for planned operations	34%
Better care for major health conditions	33%
Having the support to manage my own health	32%
Creating systems where different organisations work together to provide care	31%
Using technology more to make the NHS more efficient	30%
More focus on reducing things to prevent ill health such as smoking, obesity, alcohol & air pollution	28%
Being able to access care through the use of technology	27%

‘NHS have enough resources and should use them more efficiently. Too many specialists with no accountability. Often info is conflicting.’

‘There is a lot of duplication of notes and appointments with same doctor or consultant which do not take treatment any further and just go over ‘old ground’.’

‘Having yearly health checks for adults and maybe more frequently for children, the elderly and sick to prevent illnesses before they occurred or prevent existing ones from getting worse.’

Developing local services

‘They need to create more spaces to hear patients’ voices and actually take them on board.’

‘Listen and put in practice patients’ opinions.’

‘Keep people regularly informed by different means of communication.’

Of the Enfield residents, who participated in research carried out by Healthwatch Enfield, 59% indicated that they would be interested in helping to develop the local services by sharing their views and opinions. In return, they asked for more communication using clear and accessible information alongside commitment to listening and responding to feedback.

The most favoured way to engage local people in conversation, based on the available sample, is via an online survey (48% of respondents), a telephone chat (16% of respondents) or a public meeting (15% of respondents).

In focus: services for individuals with a Learning Disability, autism and / or other disabilities - listening to service users and their carers

During May 2019 Healthwatch Enfield engaged with 165 individuals with Learning Disabilities, autism and other disabilities, and their parents and carers to listen to their experiences of current health services and their thoughts around the NHS 'plans for the future'.

165 local people who engaged in conversations, shared their views:

- through responding to an Easy Read survey. 50 responses were collected from:

	No. of individuals*
Person with a Learning Disability	33
Person with a Autism	7
Person with Attention Deficit Hyperactivity Disorder	2
Person with a behaviour that concerns or challenges	1
Other	3
Not stated	4

* Most of those we engaged with were known to services and were in receipt of support. They confirmed they had 1-1 support workers or family members to attend hospital and outpatient appointments. In speaking with Support workers and Carers they maintained that it would be almost impossible for individuals to access support without their help.

- through responding to a parent and carers survey. 90 responses were collected from:

	No. of individuals**
Carers of people with a Learning Disability	43
Carers of people with Autism	15
Carers of people with Attention Deficit Hyperactivity Disorder	57
Carers of people with behaviour that concerns or challenges	22
Other	22

**please note that this figure is higher than the total number of people engaged with due to some individuals reporting more than one diagnosis/condition

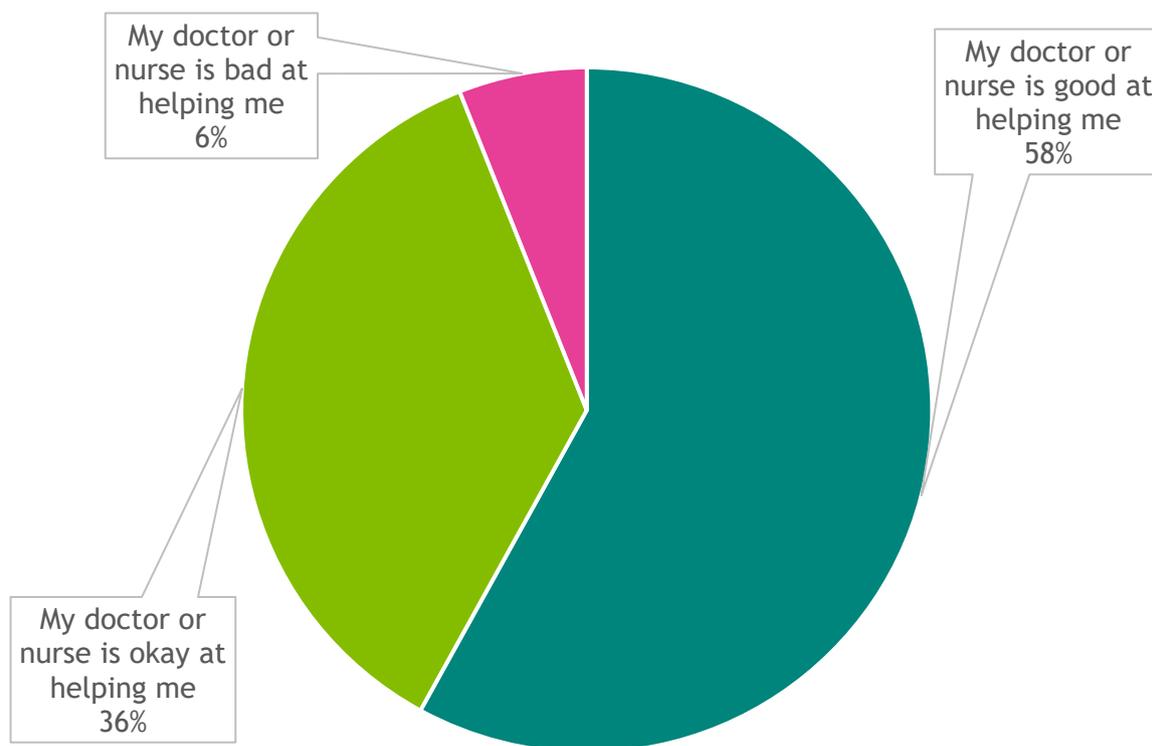
Some parents/carers explained that their child/the person they look after also have other diagnoses/conditions such as (but not limited to): Cerebral Palsy, Depression, Anxiety, Downs Syndrome, Epilepsy and Visual Impairments.

- Through attending a focus group on 15th April 2019; attended by 15 parent/carers who cared for adults with a learning disability (9 female, 6 male, aged 40-79 years, White British, Asian British and Other Asian backgrounds)
- Through attending a focus group on 17th May 2019 at a local learning disability Day Centre, New Options. The focus group was attended by 10 individuals with a learning disability (3 female, 7 male, all over 40 years. 2 Black British, 1 Turkish British, 7 White British)

Experiences of primary care services

Based on feedback collected by Healthwatch Enfield from 150+ individuals, local people with Learning Disabilities, autism and / or other disabilities do not have access to universally-high-quality primary care services in the borough.

With many reporting their experiences of seeing a GP or a nurse, there are opportunities to improve, particularly where **access to services** and **awareness** are concerned.



Of the individuals who completed an Easy Read survey (50), 58% reported that they their doctor or nurse is good at helping them.

‘My GP usually helps me with any problems I have.’
 ‘Very friendly’
 ‘They talk to me nicely and help me’
 ‘They make me feel calm.’

‘They are patient while you are trying to sit down or stand up’

‘They help me feel much better.’

36% of individuals said that they thought their doctor and/or nurse were okay at helping them, and 6% said that they were bad. Based on the analysis carried out by Healthwatch Enfield, the lower ratings were awarded due to difficulties accessing GP services, in addition to poor quality of care and poorly trained staff.

‘They don’t have training to help with autism in adults’

‘My doctors’ surgery do not give me my appointments that I need like my asthma clinic and my annual health check ups’

‘Impossible to get a telephone appointment & physically visiting the surgery to make an appointment means being first in the queue at precisely 11am, to sign up. Not much use if in bed & barely able to get to the toilet, now is it?’

‘The GP and the nurse does not seem to understand why my son wouldn’t want to be touched even when he requires to be treated’

Of the participants at the focus group organised by Healthwatch Enfield on 17th May 2019, 1 individual said that they felt their doctor/nurse at their GP practice is good at helping them, 3 said they are okay and 1 said that they are bad. All individuals in attendance need support when they attend their GP and attend with a carer or care worker.

Reviewing data collected from 90 individuals, primary care services in Enfield were rated as excellent or good by 70% of carers and parents of people with Learning Disabilities, autism and other disabilities and as poor or very poor by 30%.

Annual health checks

Annual health checks are for adults and young people aged 14 or over with a learning disability. People with a learning disability often have poorer physical and mental health than other people. This does not need to be the case. An annual health check helps you stay well by talking about your health and finding any problems early, so you get the right care¹.

Of the individuals who completed an Easy Read survey (50), 60% indicated that they have been contacted by their GP practice previously to have an annual health check. 75% reported their experience of having one as good.

‘They have always been thorough and informative with the advice given about any problems.’

‘They made me feel a lot better and made things clearer to me.’

‘They told me what was happening and about my health.’

¹ More information available at <https://www.nhs.uk/conditions/learning-disabilities/annual-health-checks/>

Those who rated their experience of annual health checks as ‘bad’ or ‘okay’ did not find the checks to be thorough or comprehensive.

Of the attendees at the workshop on 17th May 2019, all reported being invited for an annual health check and getting reminders in the post. Some individuals explained that their experience was good as they get to have their tablets checked.

Feedback collected from 90 parents and carers of people with Learning Disabilities, autism and other disabilities indicates that 33% of their relatives were invited for an annual health check. Data analysis carried out by Healthwatch Enfield indicates that there may be **issues with the quality of checks on offer**.

‘This was very basic, GP asking questions about how she is. I would prefer blood tests, urine checks, breathing and a lot more.’

‘I think it was brilliant.’

‘But only once - when they were 14 - not seen since and they are nearly 16 - was more of a chat with me - Dr didn't really examine my child or do any tests - just flagged I need to think about how we transition them to adult NHS services which is scary for me’

‘Brilliantly done.’

‘Asked relevant questions for 30 minutes, but not enough physical checking.’

‘Very quick, not very thorough’

Experiences of hospital services

Based on feedback collected by Healthwatch Enfield from 165 individuals, local people with Learning Disabilities, autism and / or other disabilities identified instances of good practice, with 64% of those who completed an Easy Read survey (50), rating their experiences of hospital services as good.

‘Always found GPs I've seen, and the nurses have been when visiting urgent care dept.’

‘The staff are excellent, attentive and encouraging when it comes to my misfortune.’

‘They explain the different types of tablets.’

‘They give me lots of checks’

Despite this, difficulties around communication and lack of staff awareness, meant that 25% and 11% of respondents to the Easy Read survey, rated their hospital visits as ‘OKAY’ and ‘bad’ respectively.

‘The doctor did not speak in plain English and they do not have any information in easy read information.’

‘They need more training how autism affects people’

‘Nursing staff over recent years have become careless, uncompassionate & downright lazy, due to the managers getting bonuses every time they save money on their ward.’

At the focus group organised by Healthwatch Enfield on 15th April 2019, individuals spoke of long waits to see consultants, particularly for Epilepsy. One individual said that they had to get the support they needed privately, and that Enfield does not have an Epilepsy nurse. Individuals spoke of the usefulness of hospital passports and the convenience of hospital transport dropping them outside the hospital entrance. However, some individuals felt that the hospital passport should be made shorter to make it easier for professionals to read.

Conversations at the session on 17th May 2019, highlighted that doctors / nurses are good at helping individuals with Learning Disabilities, autism and other disabilities but the health professionals tend to **communicate with carers rather than patients directly**. 1 individual said it is ok when they visit the hospital, but that they find the visit boring. Based on data collected from 90 carers and parents of people with Learning Disabilities, autism and other disabilities, hospital services has been rated, as per the following:

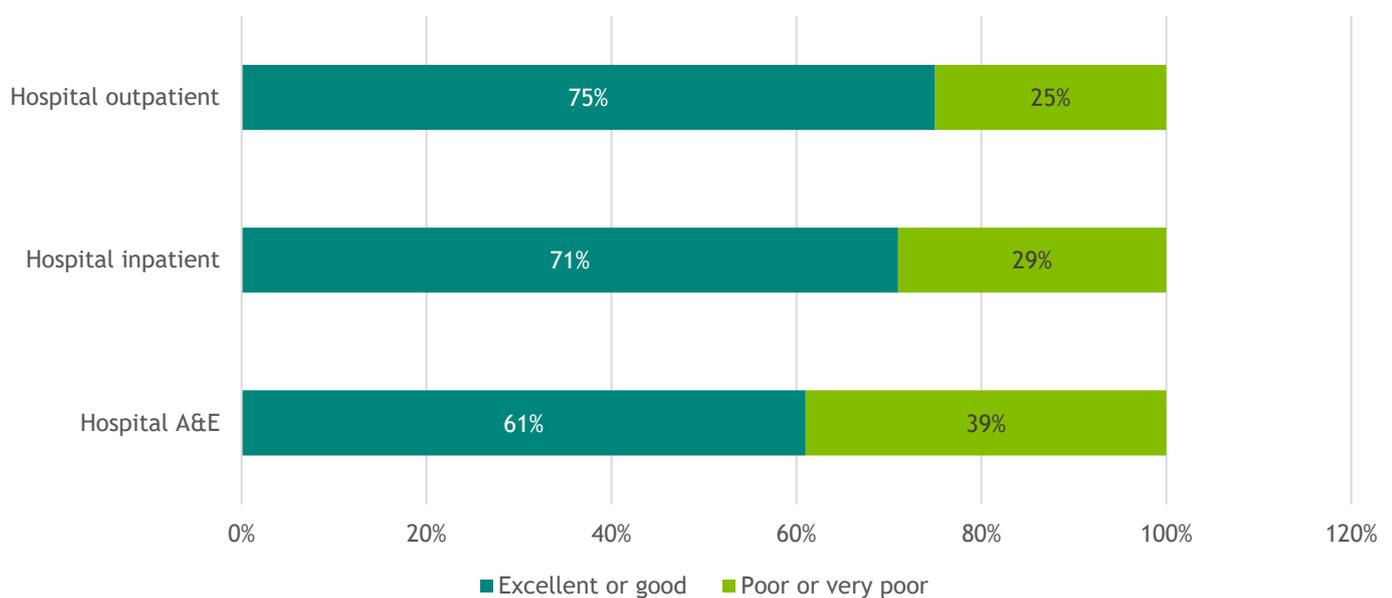


Figure 1. Hospital services rating by carers and parents of people with Learning Disabilities, collected in Enfield

Learning Disabilities, autism and other disabilities access a wide variety of health services. The quality of these is inconsistent as staff do not seem to have received appropriate training and are **unable to communicate effectively with people with Learning Disabilities, autism and other disabilities**. Local people have also raised their concerns about long waiting times.

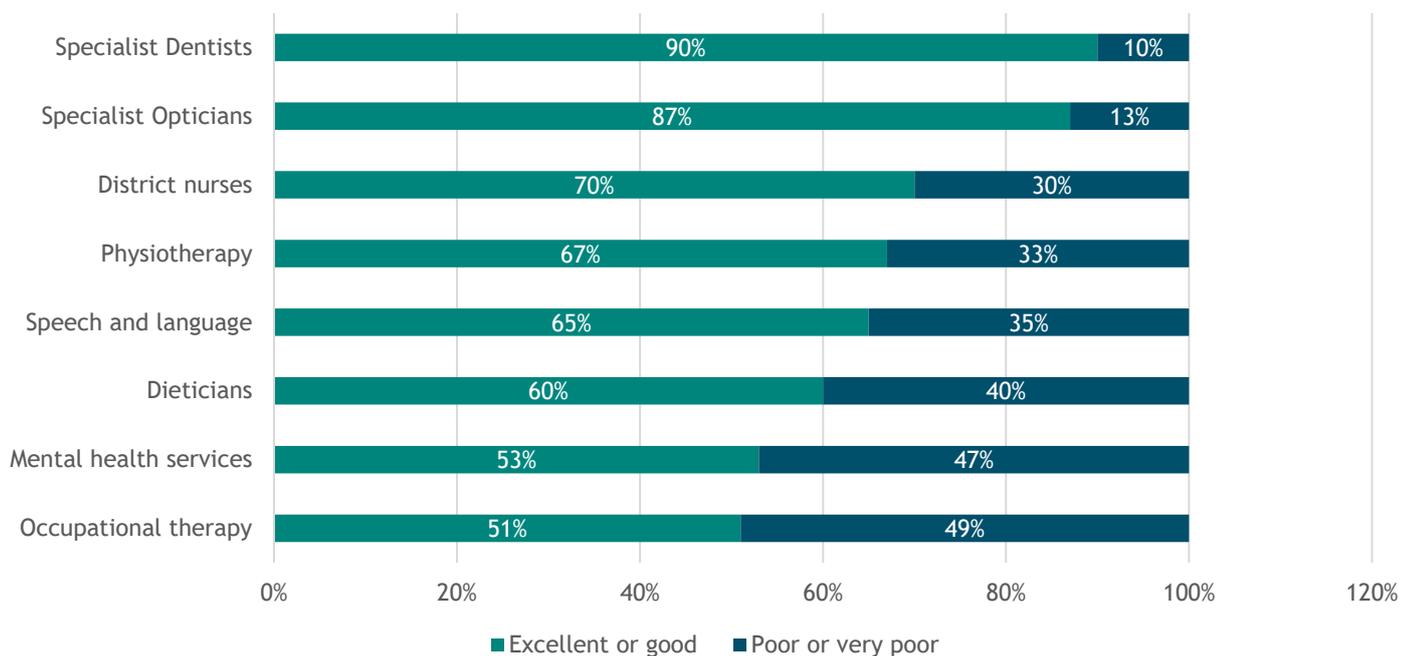
Of the fifty people who completed the Easy Read survey, 59% indicated accessing support from: diabetes teams, psychiatry teams, dentists, opticians, audiologist, podiatry, school nurses, private doctors, urologists and haematologists. 56% of those accessing additional support, reported the health professionals were good at helping them.

‘Because they did the bandage properly.’
 ‘They help you to improve your health and understand what you are feeling.’
 ‘They are very responsive and understanding.’
 ‘They talk to me nicely.’

33% of them stated that other health professionals were okay at helping them and 11% said they were bad. This is due to **difficulties around communication and lack of staff awareness.**

Participants of the workshop held by Healthwatch Enfield on 17th May 2019 reported using a variety of other local health services such as **community nurses, district nurses, audiologists and speech and language therapists.** Individuals reported that their experiences have been positive as the staff are friendly, but one individual reported that they haven't seen the district nurse for a long time and don't know why.

On average, 68% of carers and parents of people with Learning Disabilities, autism and other disabilities (90), rated the health services their child/dependant receives as excellent or good.



‘We have been seeing medical professionals since my son was 8 months old and we have been treated really well’

‘OT has been amazing. Lots of practical help and great communication.’

‘Physio, excellent, always been there regularly attended the meeting.’

‘The speech and language therapists and occupational therapists have been very helpful for my son to progress in his social, emotional and communication skills. They have good and consistent service.’

Of the carers and parents who rated the health services their child/dependant receives as poor or very poor:

- 47% justified the rating due to **difficulties accessing services** and long waiting times

- 26% based the rating on the **poor quality of care** and a **lack of understanding** amongst professionals of the needs of individuals with a learning disability, autism or other disabilities

‘The CAMHS service took 8 months to put the support in place’

‘The problem has not been solved and we are now in a holding pattern, having been told there are no staff, or that we are again on a waiting list. We regularly contact the service for updates. We urgently need some help and therapy for my child’

‘SLT - nowhere enough staff to deliver the service needed. OT - excellent if you can get it, but very difficult to get - not enough therapists’

‘They didn't listen to my son's sensory issues and caused unnecessary stress.’

‘Hospital appointments when our son was younger were a minefield. They either ignored him, asking us the questions, or went OTT trying to appear "autistic friendly”

‘Health professionals just don't understand autism. There is little compassion, understanding or flexible thinking.’

Delays in treatment due to having additional needs

37% of parents and carers of people with Learning Disabilities, autism and other difficulties (90) reported that they felt their child/the person they care for experienced delays in receiving treatment due to having additional needs.

‘My son lack of diagnosis meant that he was denied support for 2 years.’

‘Doctors in the GP did not have the expertise of his profession to have sent my son to a diagnosis in his first years of life, and now with 5 almost 6 years not yet begin to receive any professional training in therapies, is still on the waiting list.’

‘We had to go to several hospitals see what was wrong. It wasn't until he was 14 that his problem was correctly diagnosed’

‘I missed them calling our name because I had to remain outside to keep my son away from the crowd and the staff could not call me in. they were aware of my crisis because my son was shouting and trying to run away from the crowd before I eventually took him outside in the cold’

Communicating effectively: do you understand what the doctors and nurses are telling you?

Communicating effectively with patients is a subject of many studies with a clear indication that it is a necessary skill to master in order to maximize positive health outcomes for patients. Based on the data collected by Healthwatch Enfield from 165 individuals with Learning Disabilities, autism and other disabilities, and from their parents and carers, it is an area that requires urgent attention as, on average, **50% of individuals do not understand what the doctor or nurse is telling them.**

Feedback from 50 Easy read surveys, indicates that 46% of respondents feel that communication with healthcare professionals could be improved.

‘Actually listen and explain in a way people with autism can understand’

‘Use less jargon.’

‘Easy read information.’

‘Talk more slowly when they are talking to me.’

‘To visit the place and meet all the staff that will be looking after you on the day and they show you the equipment they may be using on you on the day and talk to you in plain English and have information in easy read to give you’

‘Doctors and nurses talk too fast so I can’t grasp what they are saying. Talk in simple language more slowly, with pictures and Easy Read’

At the workshop held on 17th May 2019, 2 individuals reported that they do understand what the doctors/nurses are telling them, but not when they are stressed. 4 individuals explained that they don’t understand what the doctors/nurses are telling them. They explained that they need the doctor/nurse to repeat things, speak slowly, use picture aids, use basic Makaton signs and talk directly to the patient (not the carer). Individuals explained that it is helpful if the learning disability nurse is aware of their attendance at an appointment.

Of 90 parents and cares of people with Learning Disabilities, autism and other disabilities, some identified areas of good practice but 55% felt that staff did not demonstrate good levels of awareness and could not communicate effectively.

‘They spoke directly to my daughter and listened to her views.’

‘With one child mid spectrum all staff apart from one (years ago) have made efforts to adopt language listen to my child n listen to me as I need to advocate for him’

‘Varies - most communicate through me and only speak to my young person to say hello or can I see your arm. Nothing ever to ask him why he is there or what he wants.’

‘Mental health services therapist had little understanding of autism, no time to establish a rapport with child - then discharged’

‘Have explained many times when attending appointments, the nature and behaviour of my son, to no avail’

‘They do not understand autism- just the name.’

Improving experiences of using health services

Analysis of 165 surveys and feedback collected from focus groups identifies the following areas for improvements, as articulated by people with Learning Disabilities, autism and other disabilities, and their parents and carers:

- **embedding the principles for reasonable adjustment within health services.**
This would mean that appointments for patients with Learning Disabilities, autism and other disabilities are always offered on time to minimise stress and anxiety so that their behaviour does not become challenging; allowing for additional time with clinicians and giving consideration to environment
- **improving access to services**

‘The waiting time for appointments is not good and I’m aware that this is across NHS but with a child with additional needs accessing support and advice asap is essential to support family and child.’

‘More specialist services with higher levels of expertise across more complex needs.’

‘More access to speech therapy and physio occupational health.’

- **investing in staff training to improve levels of awareness and the ability for staff to communicate effectively**

‘For staff to really listen to what is being said to them. For all staff to be sufficiently well trained to be able to recognise hidden disabilities in all its guises’

‘Greater awareness around needs of Autism and how to work with the child’

‘listening and being patient. making extra time.’

‘knowledge + awareness of the how autism affects anxiety and accordingly made adjustments/preparations’

‘An understanding that children with disabilities can react differently’

It is also worth highlighting that **65% of parents and carers** of people with Learning Disabilities, autism and other disabilities (90) **indicated they had limited or no support available to them.**

‘The support is very sparse and there is not a clear directory of what is available to support a child with needs. It is not joined up and I feel that I am often breaking down in tears and then someone then refer me to services. It shouldn’t be like this.’

‘Not very good. We appreciate the efforts of some services, but as I am still working, I can’t access many of their services’

‘None, no emotional support/ counselling’

‘Poor... everything I have learnt, I’ve taught myself. Most professionals treat me like I know less than nothing and am a similar age to my child, when I’ve been managing, researching, investing, advocating, chasing his care for his whole life.’

‘So far I’ve not had any support, have to do everything on my own.’

