

Transcript from ZOOM calls, Face to Face Event and Survey between week of 13th to 20th May 2022

Do people who work in healthcare know you have a Learning Disability or Autism?

'I have to remind people a lot that I have Autism, especially at hospital'

'I go with a carer so usually people talk to my carer'

'The only service apart from my GP that is aware of my Autism is specialist dental service. This is really stressful at hospital where I have to keep telling them and the message doesn't seem to get through. It would help me a lot if they did know. I want them to know so it's easier for me to do the appointment'

'I'm ok talking to people if I know them and if I don't know them it can be hard explaining things to them'

'The doctor at hospital does but my regular GP doesn't feel I have learning disabilities'

'The only time they see my two is when they have their annual review. They are nice people but they do not understand my children's needs'

'My GP does but I am not sure If I have had an annual check last year or not'

'My hospital doctors know about my learning disabilities but unfortunately, I have had to move from my old GP to a new GP as he has retired, and I decided to live alone to be independent and couldn't stay with my old one. At least they phoned me'

'I'm an adult and when I go for check-ups, and I have my dad with me and that's a good thing'

'My doctors do, not sure about other staff'

'My old GP retired, and the new ones don't'



'My GP does know, and they are good'

'I had a fracture and went to hospital, and they made me feel like I was attention seeking before they realised, I had a fracture'

'My GP knows all about me and I went for my annual health check-up'

'I have epilepsy, I am ok with staff at hospital. I have a bad memory and they help me'

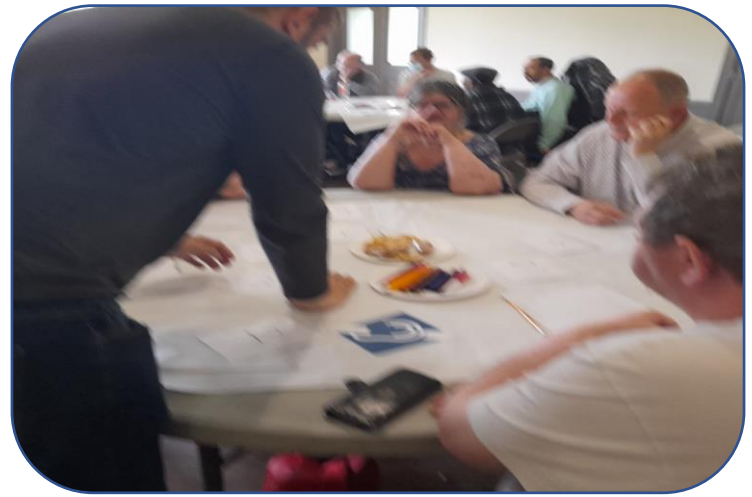
'If my son were to go to hospital to myself, the neurologist would not be able to communicate and engage with my son at all beyond saying hello or good bye. Without the carer, the appointment is useless'

'Community health know about my daughter'

'I've been in hospital and being Autistic it's not a fun time. The only time it was acknowledge when I was asked whether I have other health issues'

'I couldn't find my way round. Things didn't improve when I told. They were lovely but then I got handed to someone else and that information didn't get passed on. It was like they didn't know what to do with that information'





What are your good experiences of accessing healthcare?

'My doctor was really good to me'

'My nephew had the falls team who made a good assessment, spent time talking to him, making plans with him'

'I don't have any'

'Doctors can be really good and talk to me not my carer but people in hospital are very bad at this and it makes me cross that they speak to my carer not me'

'Optical and dental services come to home for check-ups'

'My partner went into hospital and one time he went on this ward and with his permission they put that he had a visual impairment and they put all his items in the right place'

'At my dentist they change to visors so that I can lip read when I come in as I am deaf'

'I have something where they were doing it terrible and now it's easier. It's easier to get phone appointments now. Before covid I would have to go to appointments and I have problems leaving the house and I really like the triage system, it works well for me'

'I spent a month in hospital as they couldn't find a place for me to live which was stupid as I wasn't sick. When they did get me a home, they put me in a old persons home and I am not old. It was terrible for me'

'My scan went really well'

'When my son was a child, it was very different. I spoke up for him. Its not quite the same when he's an adult'

'The chemist is good. They take me into a room to check I'm coping on the medication. You walk in and they smile at you and that helps'

'My chemist is brilliant. Charnock health. They really care'

‘Community nurses are brilliant’

‘The nurses in our practice are great and work hard’

‘When I go for check-ups, there are quite a few nice nurses that find my veins a bit easier. Other staff aren’t as good at getting blood out of me and it can hurt’

‘Pharmacy is very good at sorting it out quickly and getting it out to me really fast’

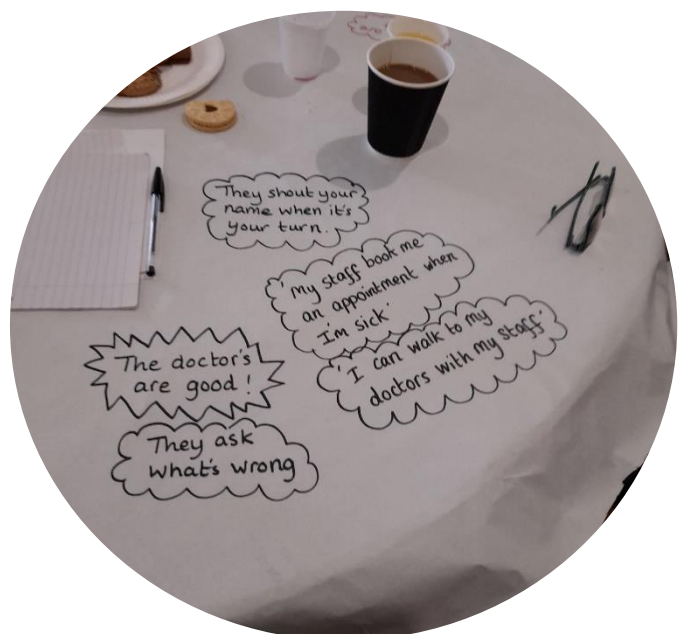
‘Spec Savers have a service where they come to your home that's a good service’

‘I've been looked after OK in the doctors they treat me well The doctors are just at the back of where I live’

I have cheque ups at the dentist and everything was fine

‘I went to hospital to get something taken out of my ear and they were really good’

‘Dentist really good as I get panicked and they swap from face masks to visors for me to lip read and then I can understand what is being saying. I don’t get that in hospitals’



What didn't go so well?

'My daughter has not experienced any good examples of health care. She is 16 years old, has autism and it feels like the services are waiting for her to turn 18 instead of providing a proactive approach and providing her with the medication which she so desperately needs'

'Get to see different doctors and this can be difficult for me'

'On the occasions my son went into hospital, they didn't want us to stay but without us I don't know how he would have coped because there was no one there with the knowledge of how to support him. We did end up staying '

'Not good'

'All the above. My daughter has autism and the Psychiatrist will not engage with her until she has attended CAHMS on six occasions. Social Care have now discharged her. She is currently managing her heightened anxiety by going to a dealer and purchasing weed . Nothing has really changed for my daughter apart from the injuries caused by her self harm has intensified when she does do this behaviour'

'I really can't remember the last time I had a good experience with healthcare. I don't have good experiences with healthcare'

'Receptionists in my surgery aren't so nice. They don't show good manners and they don't pass things on to chemist for me'

'GP services are poor, can't get through and continually put off, ring next day etc. Can't get appointment plus person nonverbal so done through parents. Receptionist very unhelpful and won't assist'

'Telephone appts, telephone contact when they ring once. My nephew has cerebral palsy and by the time he gets the phone out the caller has rung off'

'I cannot book an appointment because I cannot use the telephone and my phone does not work with apps'

Mental health services are rubbish. They don't do anything. I don't know where to get help from.

'I once had to sit in a corridor with no windows and wait for a doctor that didn't turn up for an hour this was not good for my mental health I felt very claustrophobic. They made me wait unnecessarily knowing the doctor be there at that time. I now sit outside and wait even if it's freezing cold I do not want to sit in a corridor that does not have windows'

'I have to ring dead on 8.29am This in itself is difficult for me personally to achieve because my health issues mean I cannot always function so early in the morning so making appointments with the doctor is often delayed according to my health on the day. It's difficult to get through and when it is the answer message I have to hang up and immediately dial again. It can only be done efficiently on a mobile phone, so I don't know how people without mobile phones manage it?! I have to repeat this until I get through. Then if I get through, I'm asked by the receptionist what is the issue I am going to discuss with my doctor! I told her that I would prefer to tell the doctor. The receptionist said that I had to tell her so that she could give me the right clinician. (I disagree with this idea because when I was a child I had an ex-army doctor who had loads of volumes of medical books to refer to. He didn't have the internet and he was damn good and he gave everyone all the time they needed. No one ever complained about the wait because he was thorough, and he worked very hard. He would do home visits without a second thought. Today we can look up ourselves on the internet and tell them what we think we have they have very little diagnosis to do these days.) but I said this was breaking confidentiality and it was never required 5 or 10 years ago'



'The receptionist said the partners wanted them to ask. When I asked who are the partners she said the doctors at the surgery. I don't want my GP surgery to be run like a business. AND I don't want to tell the receptionist why I'm seeing my doctor. This makes me think of an old fashioned telephone switch board where they would ask who you wanted to talk to and then they would gossip all over the village about what you are doing and talking to. I find it invasive and just awful'

'I don't trust the doctors in the hospitals. They let my mother down a lot. I cared for my mum and I have a learning disability and contacted the hospital and she went into hospital and she had a bad stroke and couldn't eat or talk at all and they wanted to move her and they went to get the tablets ready for her to move and they had a sickness bug on the ward and they didn't get her out quick enough and she died. She would have been in an old people home now if this had not had happened'

'My pharmacy is not good. They took away all the chairs in Covid and were very grumpy in lockdown'

'I have an exemption to wear a facemask and suffer from panic attacks and the hospital can be really awful if I don't have one on'

'I have had so many bad experiences I don't know where to start. It's hard to separate what is because of Autism and what is because of my gender history or other things. The only bearable stay in hospital was when I had a hospital passport and so I could tell everyone to read it. previously i have tried to give them a lot of information especially about my sensory needs. So I had medical PTSD trying to get them not to trigger that every time I'm in hospital it's so difficult I tried to give the information before I go in but nobody tells anyone and then I've had many stays in hospital where they've made me very poorly think completely disregard how badly I am affected noise especially a lot of time i have my own room and they keep leaving the door open which makes it really bad. I have to ask them every time to keep closing the door but it gets exhausting. I suppose it comes down to the NHS being on its knees but when I have tried to talk to someone about this, they are dismissive. I think but they

think I am just trying to get some kind of special attention but actually I'm really poorly and I just want my needs met'

'For me it's a communication breakdown. My husband who has a learning disability was discharged in the middle of the night. There was no communication with me. I have hearing and speech problems and they don't communicate well with me as a carer'

'Our consultant doesn't ask about all other things in my son's life and how things impact on him. It's not holistic at all'

'I have asked nurses to come into another room to remove their facemasks so I can hear them better. I have been told that they won't do this. My husband is blind and has a learning disability and he needs extra support. I need better communication from them about what's happening when he is in hospital. How they treat your partner affects my own mental health'

'I use a communication board and sometimes people can't spell so that's really rubbish as we can't communicate then'

'People don't read my hospital passport'

'The annual health checks were good and then I got asked to ring this number to book an appointment and I called it and the number was out of service'

'It took me ages to get through to the doctor I was getting so frustrated they were over 42 people in the queue I then got to the end of the queue on the phone went dead I didn't ring back for two weeks'

'Hospital appointments during covid, waiting rooms and information overload at appointments'

'My hospital passport is really out of date and I can't update it without printing another one out and I don't have a printer'



‘I spent a couple of years in a care home and it was crap. I spent a month in hospital waiting to be discharged which was very distressing. It was awful’

‘The phone queues are awful’

‘The repeat prescription service has finished last year and nothing came out how to order your repeat prescription and I had to call my GP to ask’

‘I took my son for his eye test and I booked a double appointment and he needed more time. They had nothing adapted for someone with special needs. He can read a chart but he’s got a brilliant memory and he sometimes remembers the charts. They had no vocabulary to explain to him. It was very very poor. I wondered if he really had an eye test or whether they just ticked the box ‘

‘I went to the pain clinic and he wasn’t good. I was in a lot of pain with my back and hip and he didn’t really understand my learning disability. He asked me if I wanted to talk to other people online who are also in pain. I thought to myself, how is that going to fix my pain’

‘There is a problem with the benefit system I used to get financial support for glasses but now he said change because my benefits have changed’

‘I don’t get letters to tell me about changes. Letters I do get are not in easy read. Pictures would be good’

I have been trying to get some help from mental health services for a really long time. I’ve been to IAPT groups and I don’t understand them. They aren’t right for me. I don’t understand them. I am scared because of the way I feel. I think I’m on a waiting list but I don’t know who with or when I will get help.





'The communication with receptionist is 50/50'

'Some services are dishonest wait support

for care is not free they are not being transparent

with costing's I feel discouraged'

'I used to go to the hospital regularly I have scoliosis I have bad periods I've had rubbish experiences I have bad mood swings the doctor isn't very approachable I have to take tablets to control my periods I am now going through the menopause and it's awful I have difficulty understanding information that they give they don't take time to explain my mum has to explain for me I was born with cerebral palsy I have a lot of cheque ups I have to wait a long time for appointments the dentist comes to Burton street the in my opticians is not wheelchair accessible'

'Hard to book appointments Wednesday ache very long waiting times'

'We tend to get people to home. Community opticians came a month ago but it was hard as she didn't understand what to do. All he did was shine a light into her eyes'

'Mammogram was very disturbing for her'

I prefer to talk to doctors in person I don't like talking to the doctor on the phone it's hard to understand

'Turning up for personal into appointment for consultation however arriving they do the procedure a that appointment, so you haven't had no time to prepare'

'Waiting times for appointments are too long for dentists'

'What I don't like is when the receptionist doesn't know that I have autism even after I've communicated this to them on many occasions'



'I have felt bullied for buying glasses from another opticians communications asking someone use their eyes for and when the answer to see appeared they didn't have an understanding of autism'

'I can't print the passport off because it uses too much ink on my printer'

'I had my meds in a NOMAD try and the pharmacy keeps getting it wrong'

'A range of staff accept his answers without

them exploring issues with him. He often says he's totally independent, tick. Yet he's very obviously physically disabled. This leads to inadequate support following serious falls or scalds. They ask if he can manage, want to discharge on a Friday evening, of course he says yes. This leaves me trying to pick things up at short notice and care support can't drop everything at short notice'

What Reasonable Adjustments are in place?

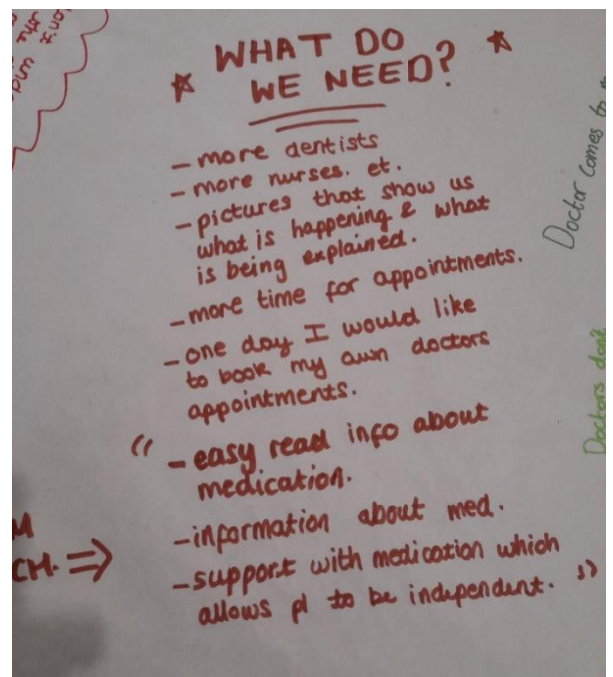
'No reasonable adjustments in place'

'No GP exception without a real tussle.

Covid jabs given in car part due to autistic person unable to go into surgery.

I had to beg for this'.

'As a carer I always arrange to stay for the visit, responses seem to rely on individuals rather than an organisational response'



'None'

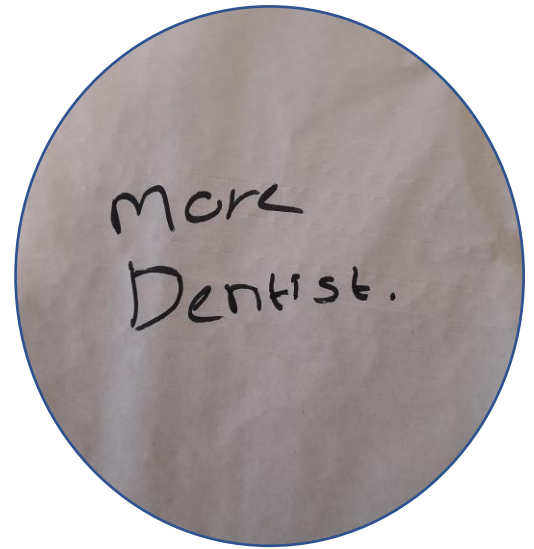
'I get my carer to attend in person

appointments and try to get **copies of letters'**

'I have **extra time** with my regular G.P. but

when I see other doctors in the same surgery

they often don't look to see that I have extra time and will not extend it. Some doctors stick rigidly to 10 minutes even when no one else is in the waiting room'



What Reasonable adjustments are needed?

'More **training around autism and learning disabilities** needed'

'**Home visit from GP** when not well or telephone reply from GP on the day'

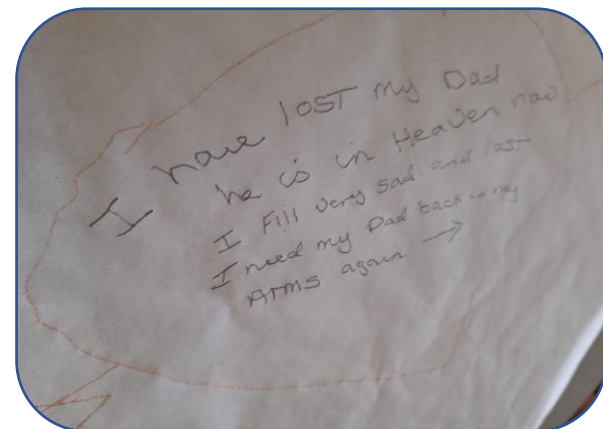
'**Access** is a problem as he keeps being allocated an upstairs room at the dentist'

'**Different phone system** for people with Autism, learning disabilities and mental health issues'

'I would like **double appointments** to give me more time to process information given'

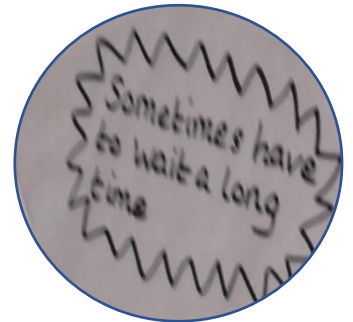
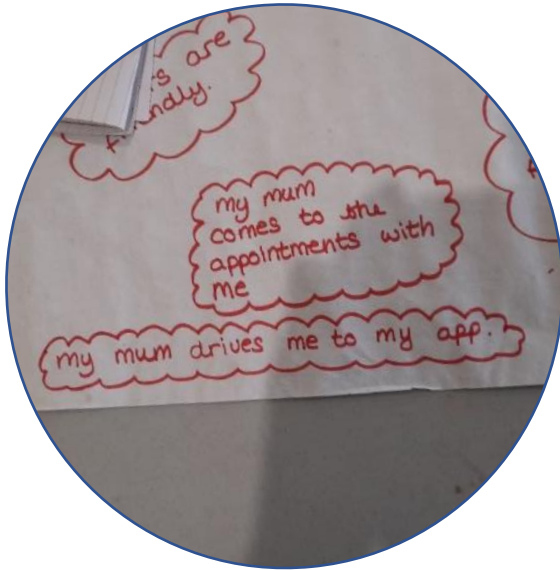
'Having someone with me at all appointments on telephone and in person to help **take notes and prompt questions'**

'I need a **full explanation of procedures weeks BEFORE a procedure**. Not on the same day. I once was referred to hospital for an internal procedure. I thought it would be a discussion but they wanted to to the procedure on the





same day. I did not have enough information in advance about what they were going to do so I was not prepared, and I broke down crying'



'Better access to services'

'More time given for appointments'

'Training in sign language'

'Pictures for what is happening and being explained'

'When going to A and E it would be helpful if there was a **quieter room**'

'Better **phone lines and better receptionists**'

'Medication instructions should be more accessible, larger phones, **Braille, easy read**'

'Ability to **book own appointments online**'

'Our community health nurse wears a **face mask with a plastic front** so I can lip read what she's saying'



‘I tried to ask for a **quiet room** often I am promised this but when I get there I might not have a quiet room and that upsets me’

‘There needs to be **more nurses**’

‘People need to **speak slower**’

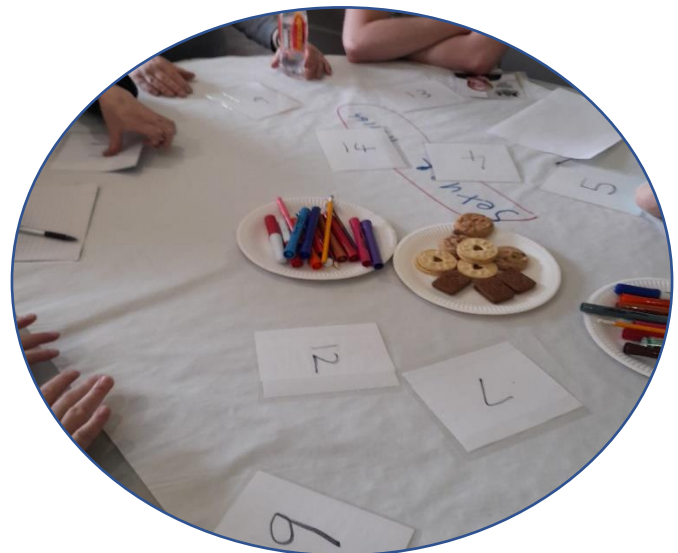
‘**Quiet rooms and quiet awaiting areas**’

‘My dream situation would be to always have a **space where I can wait** away from everybody else’

‘For me to be **called in at the right time** so that I don't have to wait for a really long time because that triggers me. I find it really difficult when things don't run to time. Time is very important to me’

‘What would help me is for doctors and nurses to be **trained** how to cope with people with learning disabilities and autism it would be good for doctors and nurses to know what it's like in our shoes’

‘I would like the option to have a **video call** with my consultant’



'I would like to have choice I would like to have a **video call** or a **face-to-face** appointment but I would like that choice to be mine.

There is often so much information, I cannot remember. I would like to see **clearer labels of bottles** and **clearer instructions** on how to take my medication maybe in **easy read**.

I need **more time on the phone** to explain what I need.

I don't find talking on the phone easy'

'Because the phone lines are so complicated, I often do not do it and have to wait for people to come to do it for me'

'I would like that always to be **someone at the main door of the hospital** to help people find where they're going. I've been told there should be a PALS person but these days nobody ever seems to be there'

'I would **more pictures in hospital** because I don't know some of the words for the departments and can't find my way round on my own'

'I'd like **changes explained** to me'

Some pharmacies charge for **deliveries**. The **charges are too expensive'**

'They need to have **more understanding'**

'Letters in easy read and **large print'**

'Don't feel doctors and hospitals don't know the **Accessible Information Standard exist'**

'All letters should be **easy read'**

'**Having people who get to know people with additional needs** is essential to good practice'



I wear a lanyard and yet I still get asked to wear a mask and refused to be seen unless I wear a mask'

'**Speak to me and not my carer.** I have a right to be spoken to by professionals'

'**Named people** who we could go to to say we are having trouble with certain health services'

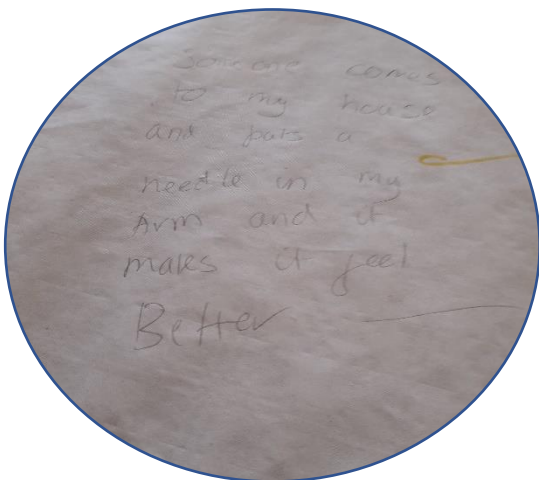
'More physical **accessible doors that open electronically** need to be in all spaces'

'**More transparency** – you put information in but you don't know what happens to it. Hospital records are not available to us. No one explains why and I worry this is because they do not want to see what is written about us'

'I find sometimes doctors can be very abrupt I'm very unsympathetic to your problems at falling surgery Hillsborough they need to go on a training course and be made **more sympathetic towards people**'

'We need **more doctors and more nurses** is too long to see one '

'More **easy read information**'



Anything else that you would like to tell us

‘Just very disappointed that there seems to be a lack of support for children with Autism’

‘Poor service from medical professionals in general. More understanding and empathy of disabilities needed and to not put obstacles in the way to accessing services’

‘I take medication for my mental health, and I work nightshifts and that can be hard’ ‘There doesn't seem to be a flag system in place. My nephew stopped his epilepsy meds and no-one noticed at the surgery. All departments work in isolation, GPS, chiropody, consultants etc they are keen to strike them off if they miss appts. He finds using the phone difficult’

‘I once went through the stress of telephoning for an appointment which was I booked weeks in advance to talk about mental health issues. It was very important to me and took me a long time to get myself to this stage. When the doctor called she used the time to talk about statins and getting me started on statins. I was surprised because I had already been called by some other doctor who had been through all that with me. I allowed her to finish and for the second time agreed to go on statins. When she had finished I started to tell her about my mental health concerns but she said that I would have to book another appointment to talk about that. She did not have time! I was gutted! Angry! and upset! I booked another appointment with my regular doctor. The doctor called me and I told her what had happened previously. She referred me to Netherthorpe Mental Health on 1st April. I waited to hear about an appointment and rang Netherthorpe Mental Health myself to find out how far I was from getting an appointment. The receptionist told me there had been a triage on the same day they looked at it for the first time 6th April and they had discharged me. I said I have not even seen them yet so how can they discharge me. It was something to do with the triage. and they decided that the G.P. was the best person to help me. The receptionist said they don't do diagnoses at Netherthorpe. They do some sort of help for people who are

suicidal, so I was referred to the wrong place AND my G.P. had not even told me. It was now the 19 of May. I called my G.P. surgery and told the receptionist everything I had been through. She put a query in for the duty doctor. I expected to get a phone call reply, but I received a text message saying - your request has been passed to the duty job and he says you need to book a routine appointment with a clinician any morning at 8.30am. - This was insult to injury for me. To be told to go through the stress of ringing in repetitively until I get through and to be referred to as a job. I don't want my G.P to think of patients as jobs!

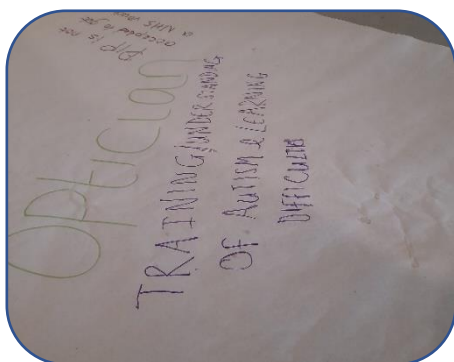
'I was brave when I went into hospital and the doctors and nurses were really nice to me and it was very good news when I could go home'

'This week I had a tablet in my tray and I do not know what it is. Its very dangerous. It's like they have made an adjustment but then they don't really implement it properly'

'I used to get letters from doctor and now I don't. It's gone downhill. They don't go the extra mile anymore to make sure you are ok'

'It is horrible. Every time I go to Sheffield teaching hospitals I end up making a complaint afterwards. It is totally horrible. In Rotherham District General Hospital there is a matron who can attend appointments with you or visit you when you are an inpatient. In Sheffield there is nothing like this. I hate coming to Sheffield and actually ask now to be referred to Rotherham where possible'

'It's really difficult to get any help unless officially diagnosed and it's really hard to get officially diagnosed'



‘Years ago we had family GP’s and we miss that as they knew us well and could respond to us in a better way’

‘I’ve been worrying about the cut back, the staff and medication shortages’

‘People with disabilities need to train staff’

‘People inquests into deaths of people with learning disabilities’

‘DNR should never happen to anyone with learning disability ‘

‘I am very nervous about getting a filling at the dentist’

‘I want to change in government that's a change that I want to see’

