



Health ambassadors Have your say Greenwich event September 2022



**better health and well being
for people with learning disabilities
and autism
in South East London**



We invited people with learning disabilities and autism to come to our event on 1st September and **have their say** about

- making things **accessible**
- **annual health checks**
- Being treated with **respect**
- **black books** and hospital passports
- their **experiences**



36 people came

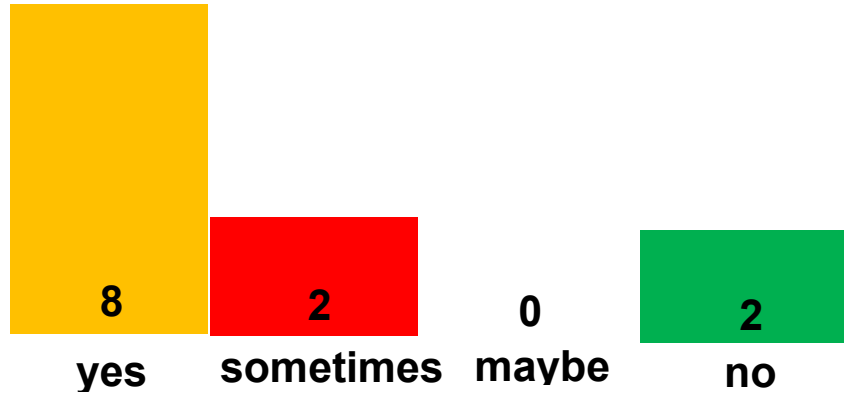
- **22 people with learning disabilities**
- **2 people with autism and a learning disabilities**
- **6 support workers**
- **3 health professionals**
- **5 project workers**
- **4 Health Ambassadors**



making things accessible



Does your GP or hospital give you information in a way you can understand?



What helps you understand?

- No jargon!
- I can't understand the leaflets they give me
- My carer helps me read the letters
- I don't get Easy Read
- I can't read small print I need Easy Read

Are you given extra time for appointments?



- Sometimes they just give me extra time at appointment, I don't have to ask
- I don't get extra time as I'm not on the learning disabilities register

making things accessible

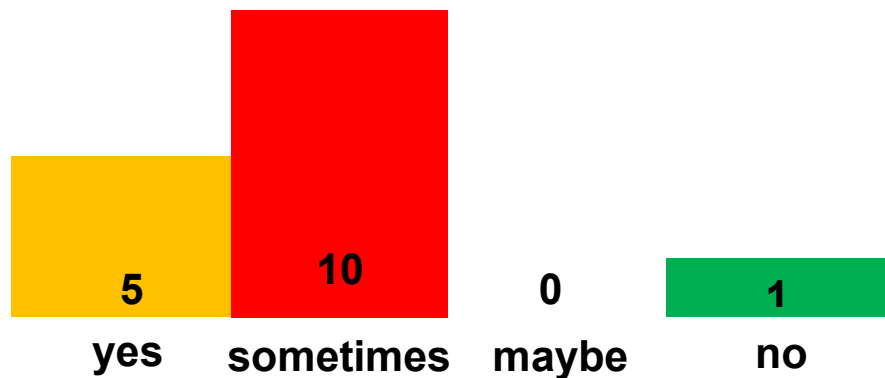


Does your doctor give you time to think and check you understand?



- They ask me a lot of questions very quick
- They don't stop to check my understanding
- They expect answers quickly
- I have to ask the doctor to slow down
- They give me leaflets about what they are doing so I understand
- I ask the doctor to repeat himself

Do people make changes for you because of your learning disability or autism?

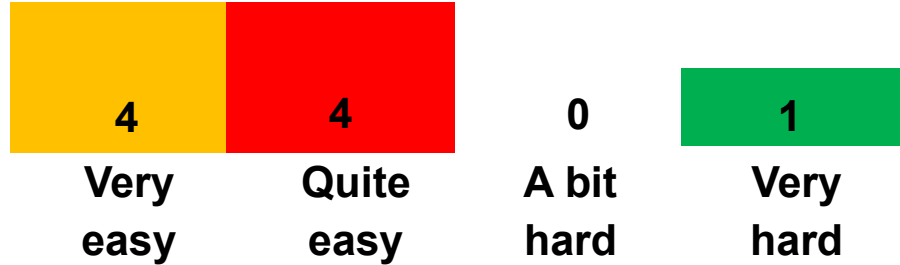


- They help change appointments when I need to
- They check my understanding
- They phone my carer to see when the best time for an appointment is

making things accessible



How easy is it to get in and around the building?



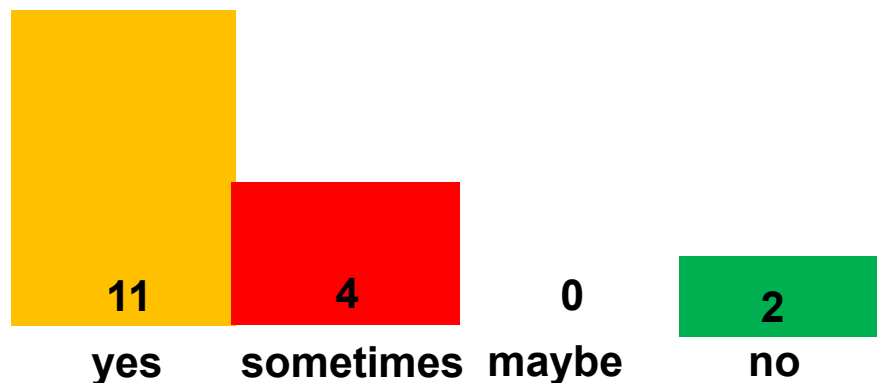
What is easy?

- All on the ground floor
- The receptionist tells me where to go
- The screen helps me by telling me where to go

What is hard?

- Small signs, no pictures
- My surgery is too big, I don't know where to go

Are you treated with respect?

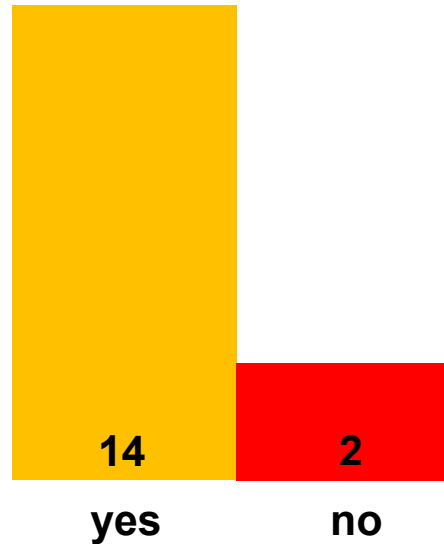


- They make decisions for me which I don't like. It's their attitude

Annual health checks



Have you had an Annual Health Check?



What was good about it?

- 3 people said they were told what would happen before things happened
- I had my health check face to face
- I understood what they were saying
- I had my blood pressure taken
- I asked the nurse to look at a mark on my leg
- 3 people thought it was healthy to get checked
- I had a flu jab
- The doctor asked if anything was worrying me or if I felt unwell
- I had my heart checked
- I had my height, weight and hearing checked
- The doctor told me to cut down on sweets and coke
- The nurse was a nice lady
- My check was successful

Annual health checks

What was bad about it?

- I haven't had one in years
- We never see the same doctor twice
- The doctor got me confused with my twin
- It's mostly online, getting a doctor face to face is less likely than winning the lottery
- The doctor speaks to my carer not to me
- I don't like having my hearing or they blood pressure done
- Since lockdown I've only had one call and that was to ask about a medication review

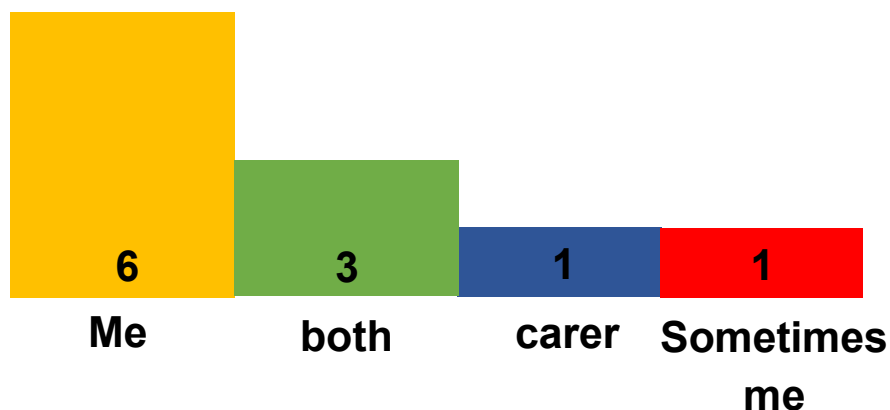
What would make it better?

- They need more training
- More information in easy read format
- The doctor should know more about me and that I have a learning disability
- The doctor should be more patient
- The nurses could do more like talk about blood pressure
- I would like them to go back to checking things like my eyes ears and feet
- Having more time
- Being able to get an Annual Health Check.



respect

Does your doctor speak to you or your carer?



- My doctor doesn't make eye contact and it would be nice to say hello and use my name
- A parent told us that the doctor called her son The Wheelchair, he is a person not a wheelchair!
- 2 people said it's good that the doctor speaks to both them and their carer
- I think the doctor should talk to me as I'm the patient
- A support worker said the GP usually wants to talk to him and not the patient, he has to avoid eye contact to make sure that speak to the patient

What went well?

- I tell the doctor what is wrong and they listen
- 3 people said their doctor treats them with respect and is never rude
- 2 people said their doctor gives them advice about eating, getting active and looking after themselves
- My doctor is always happy to see me



respect



What's difficult?

- When I was asked for a urine sample they did not help and it's difficult for me. A bed pan would be easier for me.
- Even though we ask for an appointment later in the day so I don't miss my day opportunities we can never get one
- Even though I am prepared to listen to the doctor a lot of times they are not prepared to listen to me
- My GP is ok but at the hospital it's like they have never seen a person with a learning disability before
- A student doctor told me he had had no training with people with a learning disability
- Nothing ever changes I'm still fighting for the same things
- A parent said they found it harder as their child becomes an adult
- Since lockdown everything is on-line and you can't describe what's wrong so everything is guesswork
- I have found that as I'm quiet I get treated worse because they forget about me. Drunk people get treated faster because they make a fuss
- My appointment was cancelled but they didn't let me know and I went all the way there
- Using technology to get an appointment is too hard
- One mum was asking about smear tests and mammograms for people with more complex needs. She is worried that it will be stressful for her daughter and it's hard to get information and support about this. She would like to make things easier.
- GPs don't realise they need to use easy language and support staff need to act as interpreters
- You cannot get an appointment unless you make a fuss
- You can see someone in A&E quicker than at the doctors

respect



What would make things better?

- Different families have different experiences depending on their special needs, doctors need to adapt depending on who they are speaking to
- Use more easy read
- Print out notes so that others can understand
- More flexibility and common sense such as meals for parents when adult children are in hospital
- Have more reminders about annual health checks
- Having the GP open later
- Not having your appointment cancelled
- Seeing the same doctor every time
- Listening to the parent more
- Don't rush people, give us more time
- Having a doctor with Makaton training
- Less jargon so I can understand
- Understanding people are not the same
- Better communication
- Be prepared for people with special needs
- Listen to people with learning disabilities
- More training for staff
- Being able to speak to someone so I don't have to go online
- Later appointments
- Make sure to keep on helping people be safe from COVID

respect



Receptionists

- They are nice and treat you with respect
- My receptionist is very miserable, and I'm expected to respect them even though they do not respect me.
- It's stressful to make an appointment
- They are good because they know you
- When I phone it goes to answering machine
- They expect me to know the answer to things
- 3 people said they were polite
- I would prefer them to wear face masks
- They treat me with respect, they also tell me what door to go to and where to wait. I tell them if I'm going to be late, that's important!
- When I ring for an appointment the phone cuts off
- It's hard to use the number options on the phone
- Staff should be trained in learning disabilities
- I prefer to make appointments in person
- Staff don't give me time

Health passports or black books

Who has a health passport or black book?

- 5 people have a black book
- 1 person has both a black book and a hospital passport
- 2 people have a hospital passport and though they were helpful
- 5 people do not have either
- 2 people use their black books
- 2 people use their hospital passports
- One person took it to their annual health check but neither the doctor nor the nurse filled it in
- 3 people thought the black book helped them to get looked after better



Health passports or black books



What sort of information should it have in it?

- Makaton symbols should be included
- There should be information about specifically about someone's learning disability
- There should be information about where you can go for support, including support groups in the borough and where to find financial support
- They should include crisis line emergency numbers and talking therapies. They must be easy to find a well
- They should be in a bigger font, information on how to contact you and that the doctor should speak to you face to face
- There should be lots of pictures and information
- They should include information about health checks, mental and physical health, action plans, everything about one's health, who someone's doctors are, guidance for healthy eating, phone numbers, addresses, whether their eyes are healthy, GP name and address, appointments, outcomes, end of life care, likes and dislikes

Your experiences



Bad experiences

- I don't like waiting at the GP surgery
- My GP never asks about me, so they do not know I have a learning disability. The doctor asks my mum to leave the room, but then I don't understand what is being said
- My practice joined with two others now I can't get an appointment at a time my mum can go.
- Sometimes we are 30 in the phone queue
- The GP does talk in a way I can understand



What would make things easier?

- I would like the surgery to open early, late and on weekends
- I would like to speak to a person not just an automated voice
- I would like to be able to see my GP once a month





Thank you to everyone who took part in our event.



If you would like **more information** about the Health Ambassadors, please **contact** [**HA@advocacyingreenwich.org.uk**](mailto:HA@advocacyingreenwich.org.uk)

