

Sheffield Voices Health Consultations



Sheffield Voices has been speaking to people with a **learning disability** and **autism** about healthcare in Sheffield.

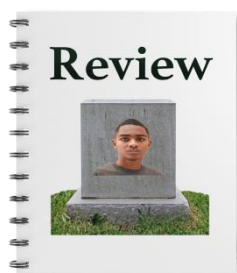
We want to know if people are happy with their **healthcare services**



We also wanted to know what they would like to **see changed**.



We know from research that **Autistic people** die 16 years younger than non-Autistic people.



We also know that people with learning disabilities on average **die 25 years younger** than nondisabled people.



We know that **autism and learning disabilities** are not the same thing, but we also know from our group members that people are struggling with **similar issues**.

How we did this



We did this by **holding different events** in different ways so that people could **choose** how they gave us the **information**.



We wanted to **hear from many people**.



We asked a lot of different **questions** about **doctors, hospital, dentist, opticians and other services** including **mental health services and sexual health services**



We sent a survey out to people using social media and through email. We also put this on our website

Six people filled out our survey



We left a mobile phone switched on for two weeks and we gave out a number that people could ring and leave a message

Eight people left a message on our phonenumber



An **autistic person** ran some **ZOOM** sessions for us.

We held one **ZOOM** session in a morning and one in an evening to give people lots of chances to attend.

Twenty-Seven people joined our **online event**



We held a big event at **Hillsborough Arena** on the **20th May 2022** and lots of people came



We played a **matching game** with pictures of **doctors, hospital, dentists, hearing clinic, mental health services** and other services, to help people say what they wanted to say



People with **learning disabilities** stood up and spoke and told us about their **experiences** of getting healthcare.

Fifty-Six people came to our in-person event

The Questions we asked



We asked the **same questions** in all the meetings on the survey on telephone message



We asked:

Does your regular **doctor and other people who work in the surgery**, know that you (or the person you care for) are **autistic or have a learning disability?**



We asked:

When you go to **hospital**, do people that work there know that you (or the person you care for) are **autistic or have a learning disability?**



We asked:

When you go to the **dentist**, do people that work there know that you (or the person you care for) are **autistic or have a learning disability?**



We asked:

When you go to the **optician**, do people that work there know that you (or the person you care for) are **autistic or have a learning disability?**



We asked:

What are your **good experiences** of getting healthcare? For example, your **chemist** might take **extra time** to explain how to take certain medications.



We asked:

What is **not working** for you (or the person you care for)? For example, using the telephone to book an appointment with your doctor.



We asked:

What **reasonable adjustments** are in place for you (or the person you care for)?

By reasonable adjustments, we mean **changes to healthcare services** to make them **accessible** for disabled people.



For example, getting **letters** from your optician in **Easy Read** or being able to stay with your carer throughout a hospital visit.



We asked:

What other **reasonable adjustments** do you **think** are needed?



Lastly, we asked:

Is there anything else you want to tell us about your experiences of accessing healthcare?

What you said

Do people know you have a learning disability or Autism?

Doctors surgery



Nearly everyone said their regular doctor knows they have a learning disability or Autism



Around **one in five** people said that other people in the surgery **didn't know** they had a learning disability or Autism.



Some people said that seeing **different doctors** can be difficult as they do not always **know** about them

Hospital



Most people we spoke to said people **working in the hospitals** don't know they have **Autism or a learning disability**

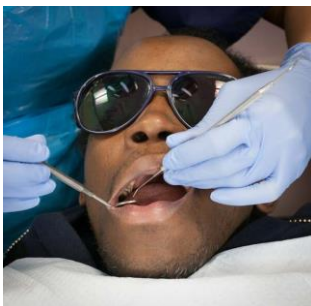


People told us that **information** about them is often not passed on



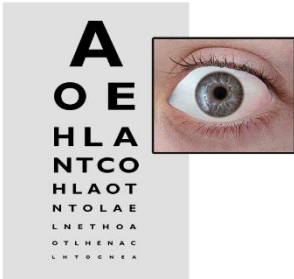
One person said they have to **remind staff** a lot

Dentist



Half the people who we spoke to said their dentist knew they had a **learning disability or Autism**

Optician



Half the people we spoke to say their optician **did not know** they had a learning disability or Autism

What you said

Your experiences of healthcare



Many people told us that they had **good experiences of healthcare** and that they had been **treated well** by services.



Some people told us **they liked it when staff knew them well**. They said it helped them to have better experiences.



However, **quite a lot of people** told us that they were not happy and that **they are not having good experiences**.

People told us that there is a lack of **reasonable adjustments** such as **easy read, extra time for appointments, quiet spaces**.



People said that there often **isn't a place** for people to go to get away from the **noise**



People also said it was hard to get **appointments**.



A lot of people said **getting through** to the doctors on the **telephone** was hard.



One person said that they had gone **without medication** because of th



Summary



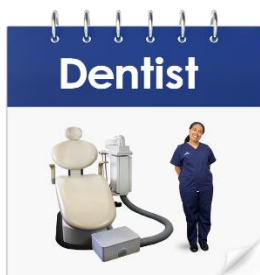
It seems there are some **good things** that are happening in healthcare and some **not so good things** that need to change



Autistic people appear to be having a more difficult time in accessing healthcare than other groups



There is a **lack of understanding** about **autism** and a lack of understanding about what **reasonable adjustments** need to be put in place



The **booking of appointments** on the **telephone** was very difficult for a lot of people but it was especially difficult for **autistic people**



There is a lack of **easy read** information available



There is a need for **medication information** to be in **easy read**



The **lack of ability** of professionals to be able to **communicate** with people with disabilities and a not their carers



The **Health Passports** don't always work for people.



People said **staff do not always read them** as they are **too busy** and there is **too much information** on them.



People said the **ink** is too expensive to print out and they are hard to update.



The **sharing of information** between professionals was talked about a lot.



People suggested having **digital passports** to help with this. A bit like a vaccine passport



The **training** of medical staff and receptionists **on how to communicate** and **make reasonable adjustments** for people was talked about a lot



People need **more time** at appointments

Accessibility was talked about a lot.



Some people are still finding that appointments are being **booked upstairs when there is no lift** and people are in **wheelchairs** or have walking difficulties





Our Gallery

Pictures from our event



Sometimes have
 to wait a long
 time

TRAINING/UNDERSTANDING
 OF AUTISM & LEARNING
 DIFFICULTIES

the doctors
 a hernia
 They took good
 care of me

I was looked after
 well in hospital.
 Nurses & Doctors
 kind.



I don't understand
 what the doctors are
 telling me my mum
 has to explain it to
 me. It makes me feel
 nappy my mum can
 explain this to me.
 AHJ

I don't understand
 what the doctors are
 telling me my mum
 has to explain it to
 me. It makes me feel
 nappy my mum can
 explain this to me.
 AHJ

Don't like needles
 Don't know who
 books my
 appointments.
 Helpfull
 Train to the doctors
 with help from carer

★ **WHAT DO WE NEED?** ★

- more dentists
- more nurses, et.
- pictures that show us what is happening & what is being explained.
- more time for appointments.
- one day I would like to book my own doctors appointments.
- easy read info about medication.
- information about med.
- support with medication which allows pt to be independent.

Doctor comes to
 Doctors don't

Someone comes
 to my house
 and puts a
 needle in my
 arm and it
 makes it feel
 Better

