

Sheffield Voices Health Consultations



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

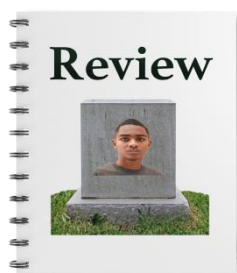
We want to know if people are happy with their **healthcare services**



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



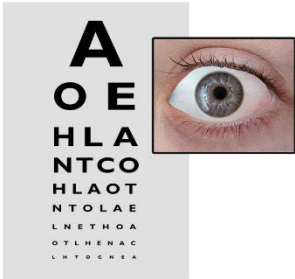
One person said they have to **remind staff** a lot

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



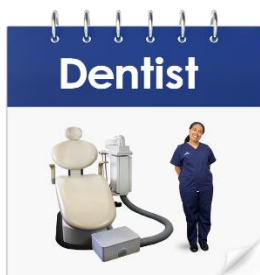
It seems there are some **good things** that are happening in healthcare and some **not so good things** that need to change



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
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Don't know who
 books my
 appointments.
 Helpfull
 Don't like needles
 Don't like health check + is scary
 (by nurses)
 Don't like needles
 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

