

What people said about getting healthcare

for adults with learning disabilities
or autism in Southwark



Easy read booklet

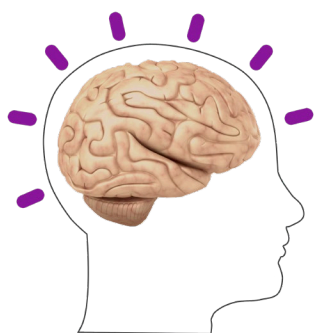
About us



We are Healthwatch Southwark.



We wanted to find out what people think about getting healthcare for adults with learning disabilities or **autism** in Southwark.

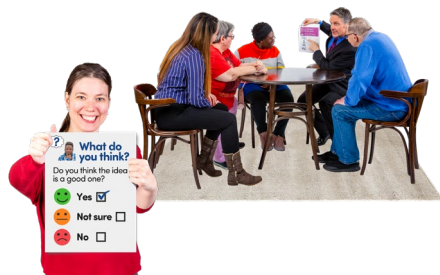


Autism is a condition that affects how people communicate, learn and behave.



We asked lots of people to tell us what they think.

About this booklet



We asked people to tell us what they think in a survey and at 3 events.

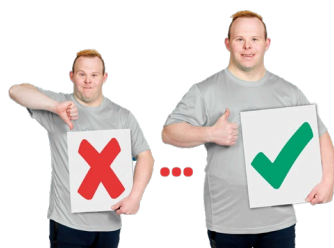


104

104 people told us what they think. These were a mix of carers, health experts and adults who get healthcare.



This booklet tells you what they said and what our **recommendations** are.



Recommendations are suggestions about how to make things better.

What people said about Staff



Staff means the people who work in healthcare.



- Staff can be rude and ignore what people say.



- Staff don't explain things clearly.



- Staff don't understand learning disabilities and autism.



- Staff don't make changes to make people more comfortable, like giving them more time to understand.

What people said about Patients



Patients means the people who get the healthcare.



- Patients feel too scared or nervous to get help.



- Patients don't know what help they can get.



- Carers are left out or ignored when they try to help make decisions about patients care.



- Some areas used by patients are not good for them, like waiting rooms that are too loud or not enough space for wheelchairs.

What people said about Operations



Operations means how services work.



- It's difficult for patients to contact services. This is because they can't find the right information or staff don't answer the phone or their emails.



- It's not easy to get appointments at a good time or place.



- It's difficult to get a **diagnosis** for autism or a learning disability.

A **diagnosis** is when an expert decides you have a health condition.



- There is no more care after patients get diagnosis or treatment.



- Changes to staff mean people get different care from different people.

What people said about Social factors



Social factors means things that make a difference to how people feel.



Social factors include when people don't have enough money to buy the things they need, or when people are lonely.



Social factors also include not having a carer when people need them.



Social factors also include when someone is treated differently because of their background or skin colour.



- It's confusing to see different staff at each appointment.



- It's tiring to explain everything again to staff. Staff should know what has happened before from the notes on their system.

Our recommendations



- Give training to staff about learning disabilities and autism.



- Remember that people often have more than 1 health condition, and that people are often treated differently because of their background.



- Choose someone at each service who can share information and make sure things happen. They will be called an **LDA champion**.



- Run events about learning disabilities and autism so people can find out about the services and support they can get.



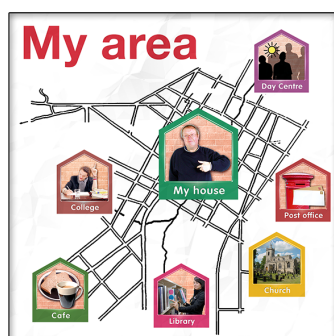
- Expert services for learning disabilities and autism should share what they know with other services.



- Make sure there is a good system to pass patients on to the service that is right for them.



- Help carers get support.



- Make sure information for the local area includes services for adults with learning disabilities and autism.



- Check that contact details for services are correct and easy to find, like phone numbers and email addresses.



- Give patients different ways to contact services, like by phone and email.



- Give information about the support people can get online and face to face, and ask local organisations to share this so more people know.



- Use the same Easy Read style for all booklets.



- Different services used for someone's care should work together.



- Use a system to make sure each person gets what they need, called the **Reasonable Adjustments Digital Flag** system.



- Make sure staff stay longer and pass information on clearly.



- Look at the areas that are used by patients and think about what people said about them.



- Make better areas for patients, like quiet waiting areas and space for wheelchairs.



- Find out what more patients and carers think.



- Find out more about how different groups of people are treated differently, using checks called an **Equality Impact Assessment**.

Thank you to A2i for the words
www.a2i.co.uk (reference 40120)

The full version of this document is called
“Empowering Voices: Examining Healthcare
Access for Adults with Learning Disabilities and
Autistic Adults in Southwark”