

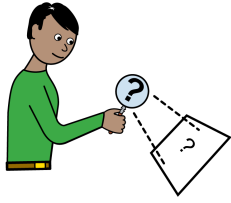
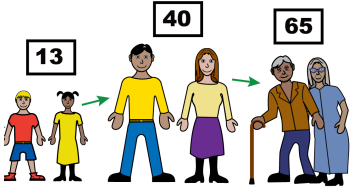
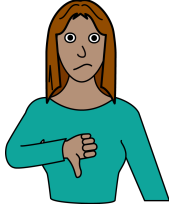
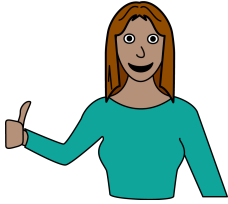
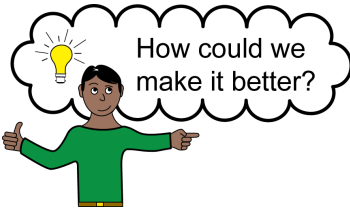
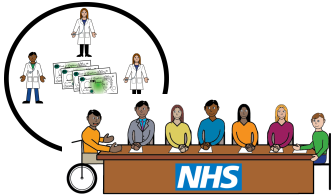

# How do autistic people and people with learning disabilities experience healthcare in Rotherham?



**October 2024**

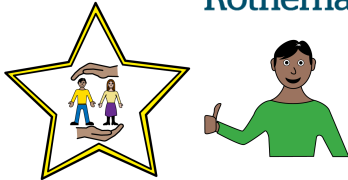
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# About us

**healthwatch**  
Rotherham

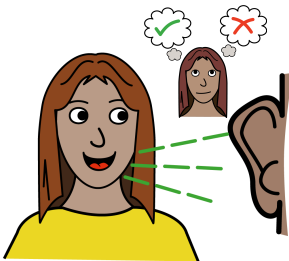


Healthwatch Rotherham wants to make health and social care services better.

We:



- help people who have a problem with their health or social care services.

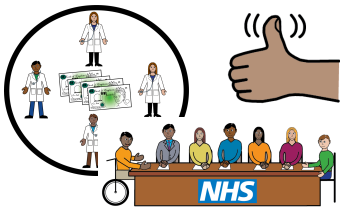


- listen to what people think about health and social care services.

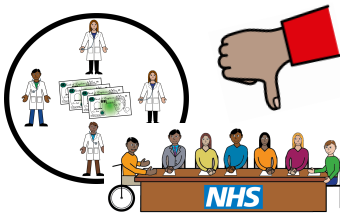


- look into health and social care services and write reports about what you have told us.

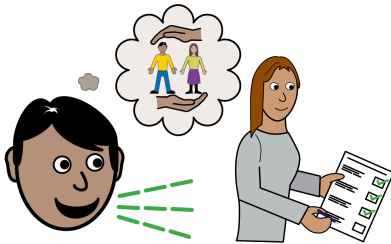
We:



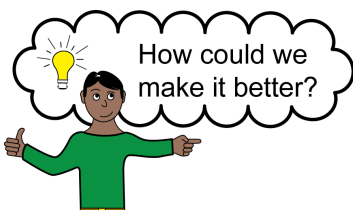
- tell the people in charge of the services what is working well.



- tell the people in charge of the services what needs to be better.



We would like to thank everyone who took time to take part in our survey.



We would also like to thank the services for telling us what they are doing to make things better.

# About this report

We wanted to know what:



- people with learning disabilities

and/or



- autistic people



Think about health and social care services such as:



- doctors

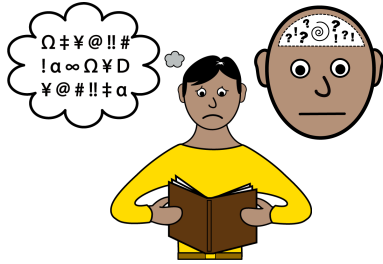


- dentists



- hospitals

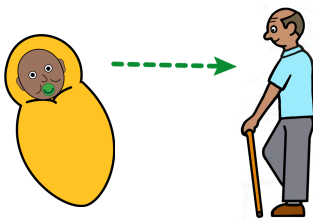
# What is a learning disability?



A learning disability occurs when something happens to the brain while it is developing.



This can happen before or during birth or in childhood.



If someone has a learning disability, they will have it their whole life.



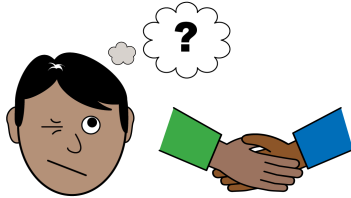
Someone with a learning disability may:



- need help with everyday activities.



- take longer to learn.



- need help to understand or remember difficult information.



How much help someone needs depends on the individual and their level of difficulty.

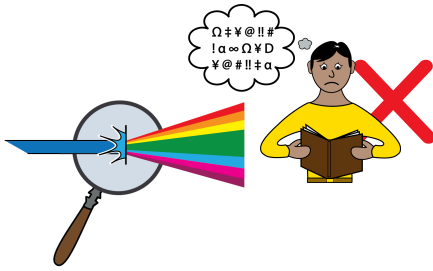


If you would like to know more about learning disabilities, you can click on this link:

<https://www.mencap.org.uk/learning-disability-explained/what-learning-disability>



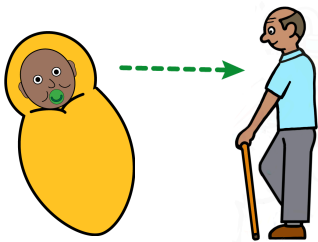
# What is autism?



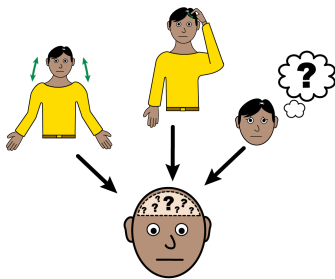
Autism is not a learning disability.



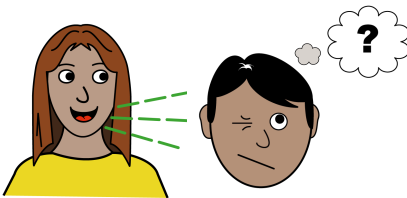
People are born with autism, we do not know what causes it.



If someone has autism, they will have it their whole life.



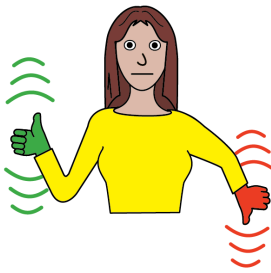
Autism makes your brain work in a different way to other people.



Autism can affect how people talk, listen and understand things.



Autism can affect how people react to sounds, smells, touch, taste and lights.



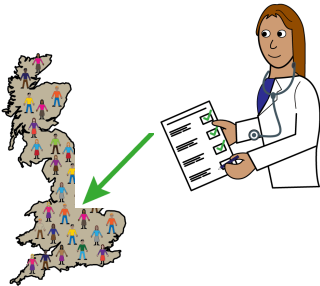
Every autistic person is individual and will find different things difficult or easy.



If you would like to know more about autism, you can click on this link:

<https://www.mencap.org.uk/easyread/autism>

# Learning disabilities and autism in Rotherham

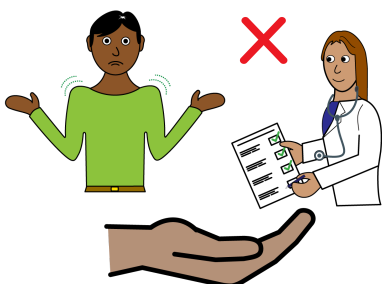


In Rotherham, doctors records show that there are around:

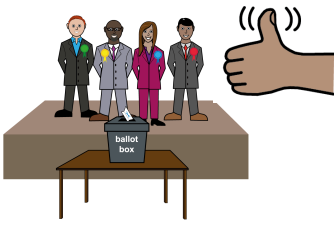
- **5500** autistic people
- **1750** people with a learning disability



However, the actual number of people with a learning disability in Rotherham is around **5200**.



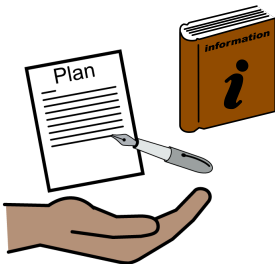
This means doctors don't know about **3450** people who may need extra support.



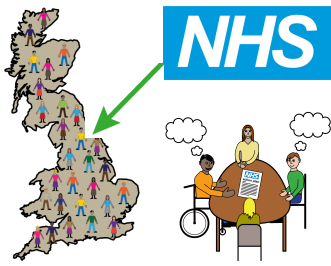
Rotherham Council are working to improve the lives of autistic people and people with learning disabilities.



Rotherham Council have written 'Rotherham's All Age Plan 2024-2027' to show how they are going to do this.



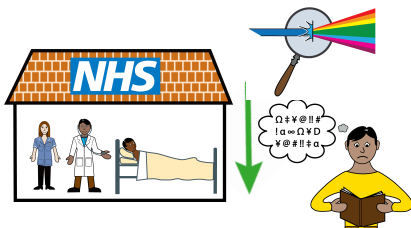
If you would like to know more about the plan, you can click on this link:  
<https://www.rotherham.gov.uk/downloads/file/3927/rotherham-s-all-age-autism-strategy-2024-2027-easy-read-pdf>



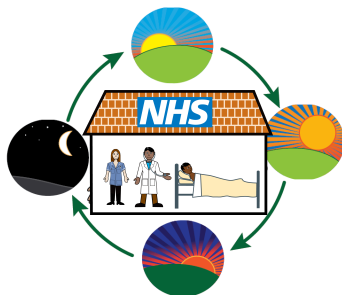
In South Yorkshire there is also an NHS Learning Disability and Autism Portfolio team who work to:



- improve the quality of life and care for autistic people and people with learning disabilities.

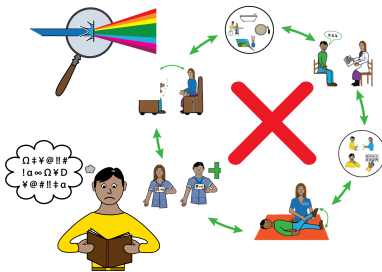


- reduce the number of autistic people and people with learning disabilities in **inpatient settings**.

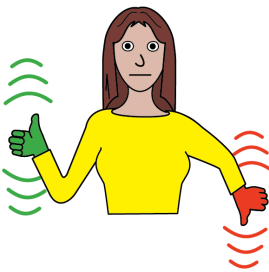


**Inpatient settings** are where people stay overnight, for example in a hospital.

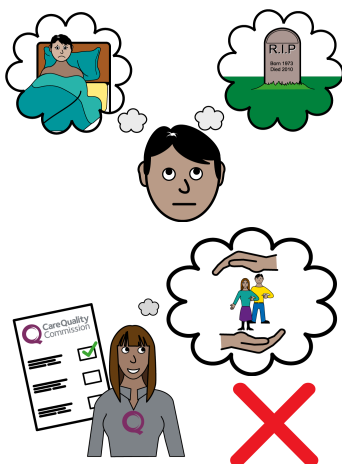
# Why did we want to hear from autistic people and people with learning disabilities?



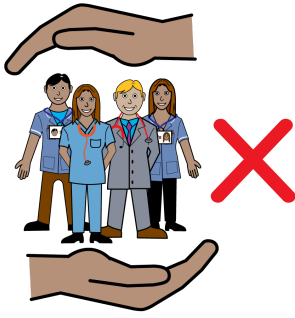
We know autistic people and people with learning disabilities face **health inequalities**.



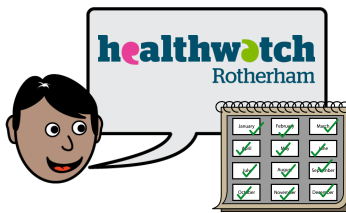
**Health inequalities** are unfair differences in health between different groups which may mean people:



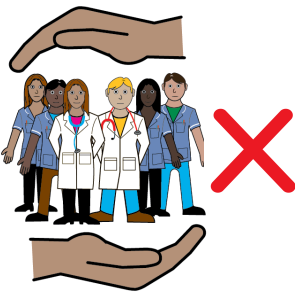
- may not live as long
- may not have the same quality of care



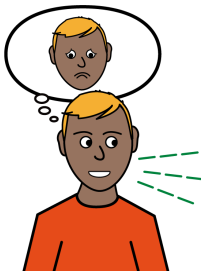
- may not have the same access to care



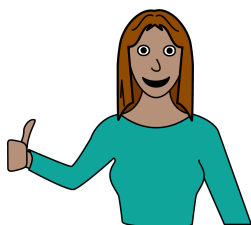
We have heard from many autistic people and people with learning disabilities throughout the year.



They told us their needs are not always met by healthcare services.



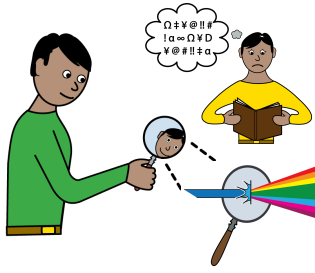
We wanted to give autistic people and people with learning disabilities the chance to tell services:



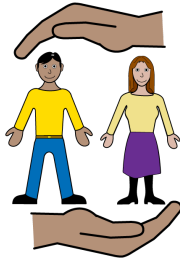
- what is working



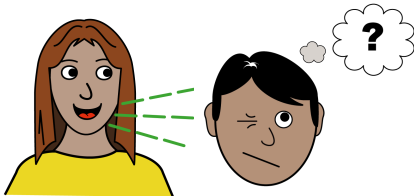
- what isn't working



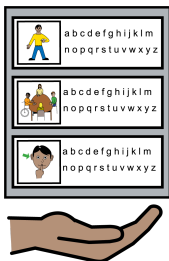
We wanted to find out how well autistic people and people with learning disabilities felt healthcare services:



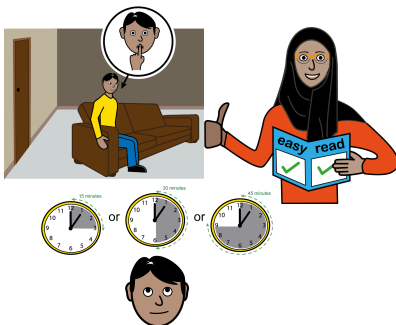
- care for them



- talk, listen and understand them

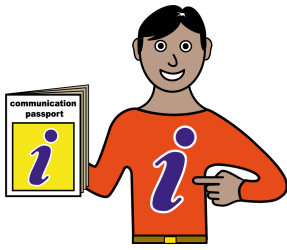


- provide **reasonable adjustments** for them



**Reasonable adjustments** are small changes that can be made to help people use services.

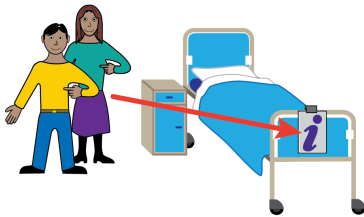




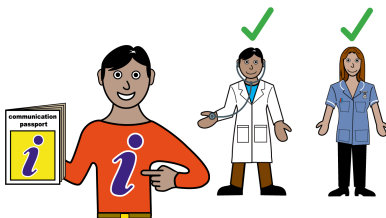
We also wanted to know whether people know about **health passports**.



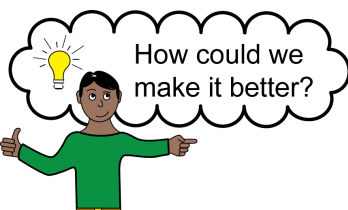
A **health passport** tells people all about you and how they can help you the best.



Health passports are also known as Hospital or Communication passports.



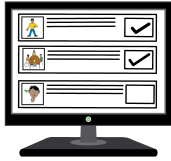
We wanted to know whether healthcare staff were using people's health passports.



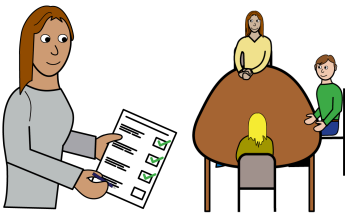
By listening to what we were told, we wanted to help health care services make things better.

# What did we do?

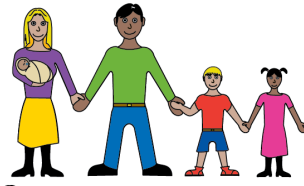
We:



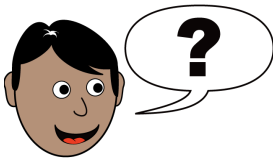
- asked people to fill in our survey online



- took a paper survey out to engagement groups



- spoke to some parents and carers



We also asked people who work in healthcare to tell us:

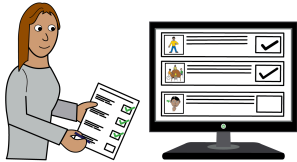


- how their service meets the needs of autistic people and people with learning disabilities

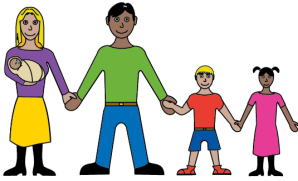


- any concerns they have

# Who did we hear from?

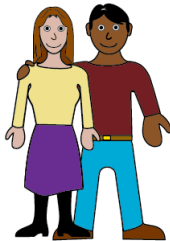


**51** people completed our survey.

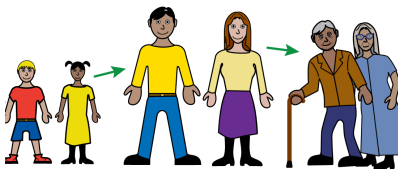


**14** parents and carers spoke to us.

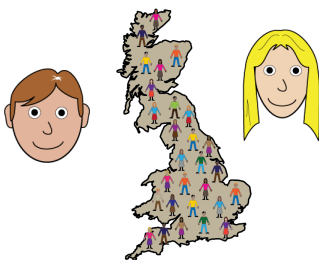
We heard from:



- both men, women and people who identify as another gender



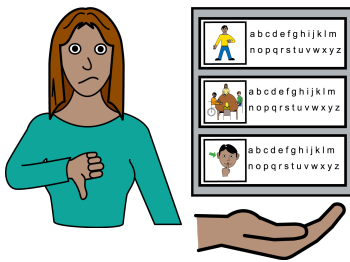
- people aged from under 16 years old to over 50 years old



- mostly white, British people

# What did we hear needs to be better?

## **Not everyone is given reasonable adjustments**



Over half of those who completed our survey weren't given any reasonable adjustments.

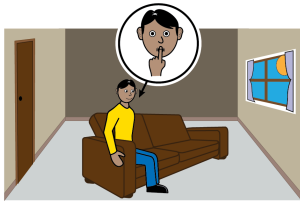


**26%** didn't know if they had been given any reasonable adjustments.

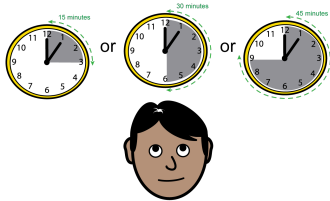


The law says that reasonable adjustments should be put in place.

Some examples of reasonable adjustments are:



- somewhere quiet to wait



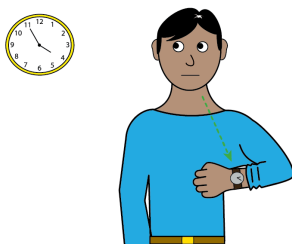
- a longer appointment



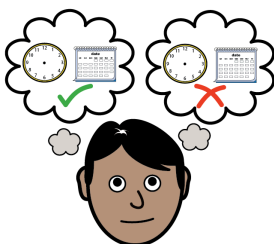
- staff to speak clearly and use easy words



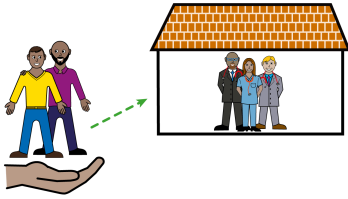
- easy read information



- having your appointment on time



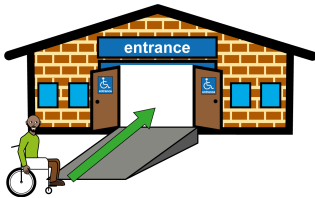
- an appointment at a time that is best for you



- having family or support workers with you

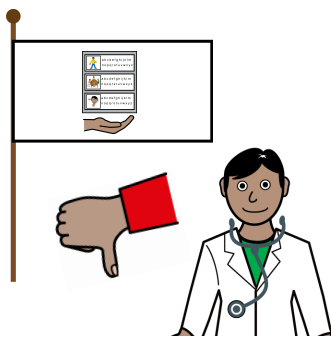


- help from a learning disability nurse

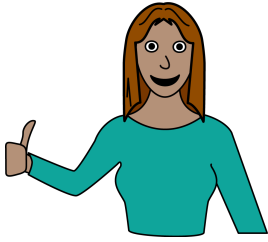


- better physical access and help to get around

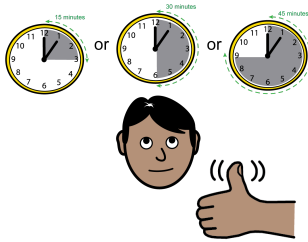
We heard:



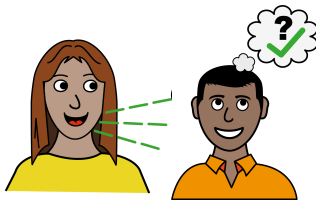
“I don’t think the flag system which says I have a learning disability works because the doctors don’t make reasonable adjustments for me”



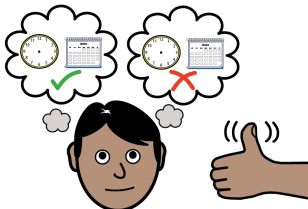
However, those who were given reasonable adjustments were really happy and told us:



“They look after me really well...explain things to me well...also give me longer appointments”



“They explain things different for me to understand”

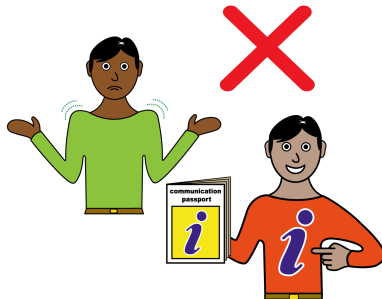


“Very understanding and flexible with appointment times”

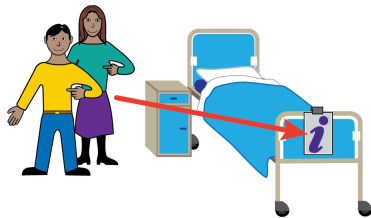


“When it comes to vaccination time, most of the staff know me and will come out to the car rather than me going into the practice”

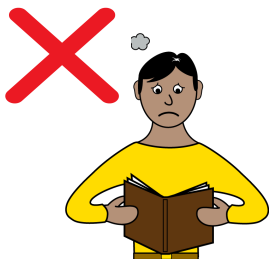
## Not everyone knows about health passports



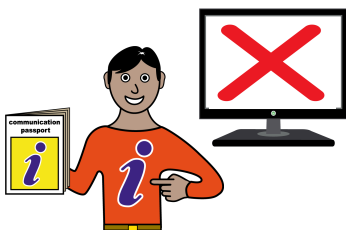
Most people who completed our survey didn't have or didn't know about health passports.



Those who have a health passport told us:

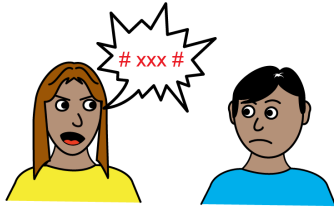


"They don't read my hospital passport"

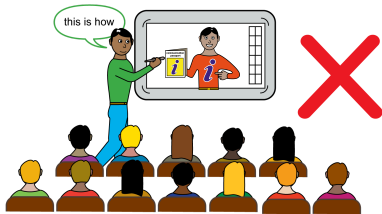


"...I have a hospital passport...[but] it's in a paper file and staff use digital non-paper care plans"





“The staff shout at me and tell me they don’t have time to read my hospital passport”

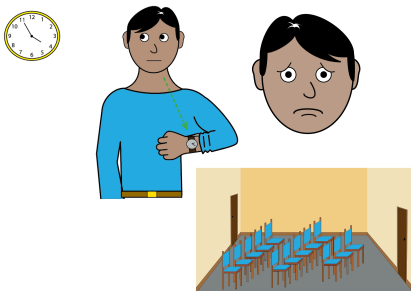


We also heard that some staff feel that they’ve not had enough training about passports.



This means they don’t know how to use them to help care for patients.

## **Hospital and doctors waiting areas need to be better**



People told us they find having to wait for long times in waiting rooms uncomfortable.

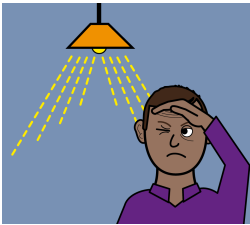
People also said they found the waiting rooms:



- too loud



- too busy/overcrowded



- too bright



- overwhelming

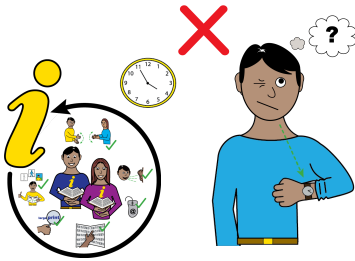
## **Communication could be better**

People told us they had problems with healthcare staff explaining things clearly.



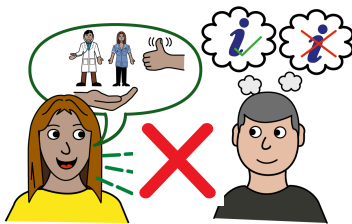


This means it is harder for people to know how to look after themselves and stay healthy.

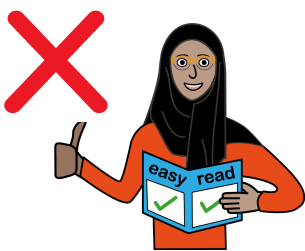


It may also mean that people miss appointments as they don't understand the letters they are sent.

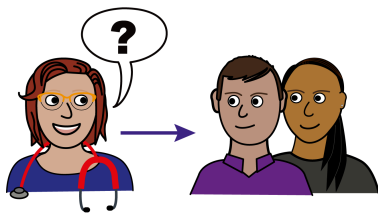
We heard:



“The doctors don't explain things to me clearly enough”



“The doctors don't send out easy read letters”

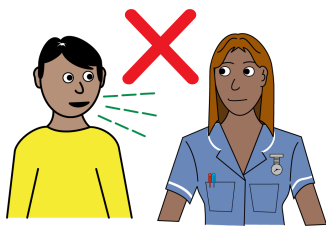


“The doctors talk to my carer and not me...just because someone is quiet doesn't mean I can't understand”

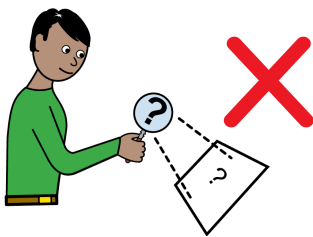


“I received a letter about my smear appointment and I couldn't read it so I had to go back to the doctor's and ask what the appointment was about”

## **People don't always feel listened to**

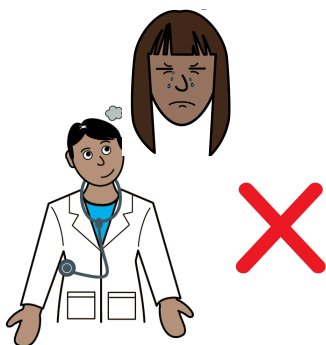


A number of people told us they felt they weren't listened to enough.

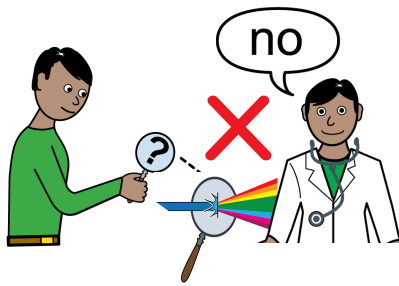


People felt their problems were not looked at properly.

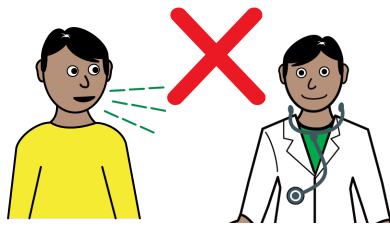
We heard:



“As I was not screaming and being loud, my pain was not accepted as being...real”

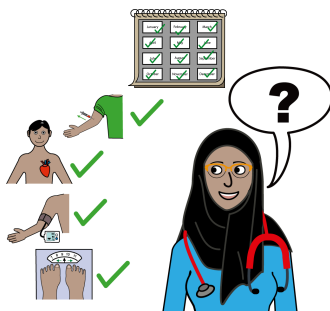


“They don’t want to investigate my problem...they just put it down to being autistic”

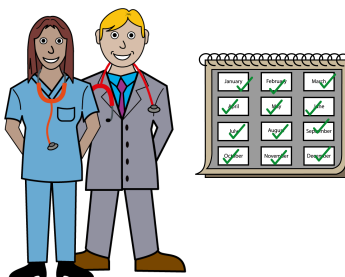


“Feel like doctors are not listening when I explain that something is wrong”

## **Not everyone is having their annual health check**



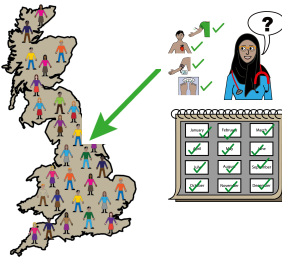
Everyone aged over 14 with a learning disability should have an annual health check.



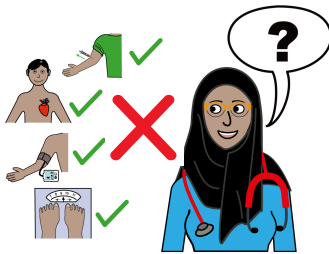
An annual health check is done by a doctor or nurse once a year.



It is done to help people stay healthy.



Only **1247** people in Rotherham had an annual health check last year.

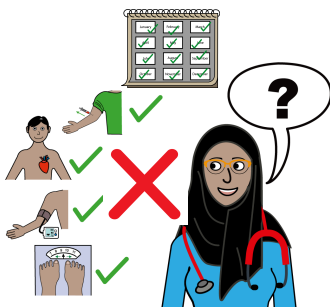


This means over **400** people on the learning disability register in Rotherham didn't get one.



Some of those may have been under 14 which means they wouldn't get one.

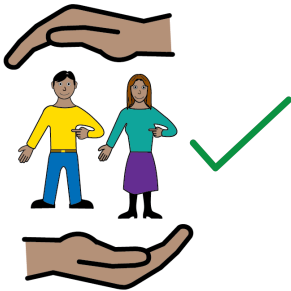
We heard:



“We are not offered yearly reviews...whereas when we lived [elsewhere]we did”

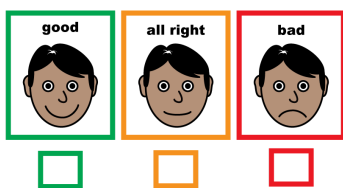
# What did we hear is working well?

## People feel safe

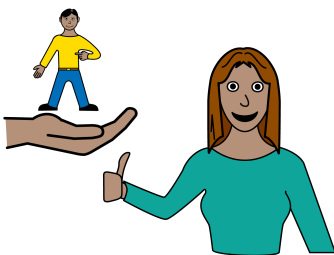


**81%** of people who completed our survey felt safe in healthcare settings.

## A lot of people feel that they are getting good care



We asked people to rate the care they were given by healthcare services.



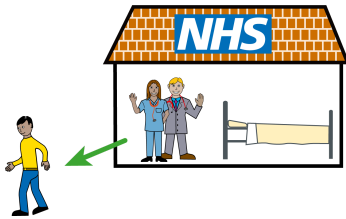
Over half told us the care that they received was good or excellent.



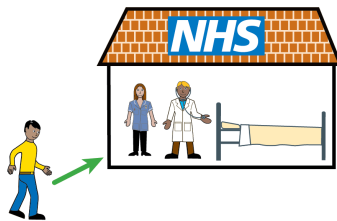
- **62%** said the care at their doctor's was good or excellent.



- **73%** said the care at their dentist's was good or excellent.

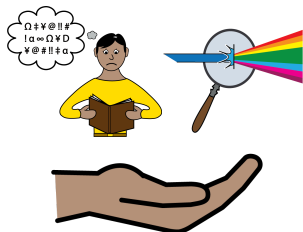


- **62%** said the outpatient care at the hospital was good or excellent.



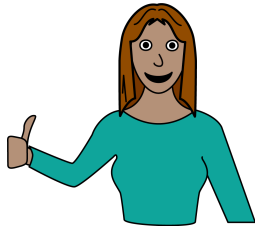
- **65%** said the inpatient care at the hospital was good or excellent.

## **Specialist support is good**



Some services provide extra support for autistic people and people with learning disabilities.

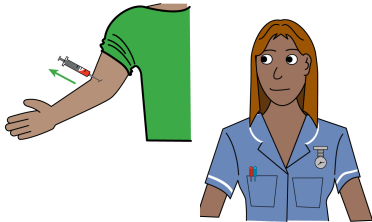




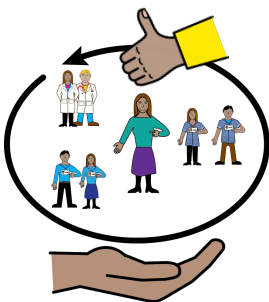
We heard examples of some fantastic care that has been provided through these services:



“The community dentist service...specialise in [treating] those who have additional needs...lovely and so understanding”

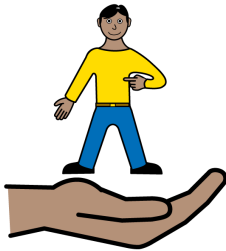


“I have my blood tests done by...a LD specialist nurse at RDaSH. I trust [her] and now am able to have a blood test without any sedation”

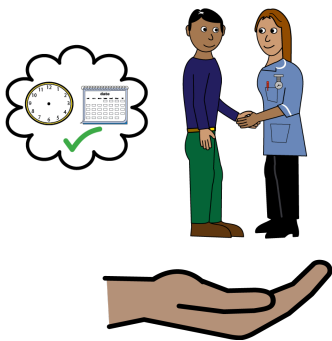


Even in general healthcare services, where staff take time to understand the individual, care is better.

People told us:



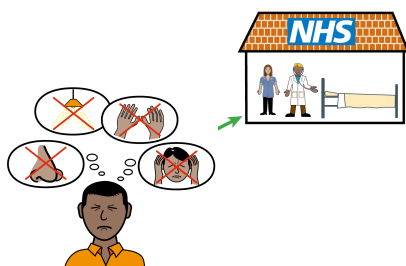
“Everyone should be supported as an individual...relationships are key to good healthcare”



“They wanted to build a relationship...first and said it didn’t matter how many appointments it would take”

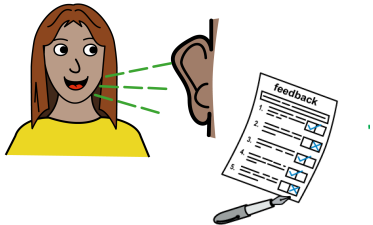


Healthcare staff suggested some quieter medical facilities could be used instead of Rotherham Hospital.

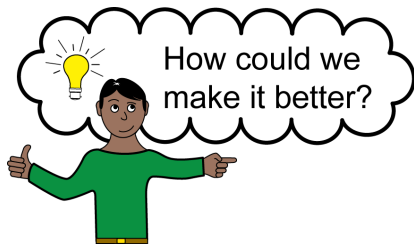


This would help those who struggle to cope at Rotherham Hospital have access to healthcare services.

# What changes did we suggest?

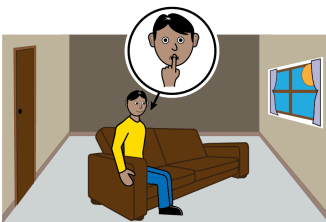


We listened to what we were told and fed this back to health care services.

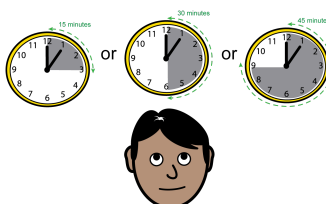


We suggested some changes they could make to help things be better:

## **Reasonable adjustments**



- quiet spaces should be available for people to wait in.



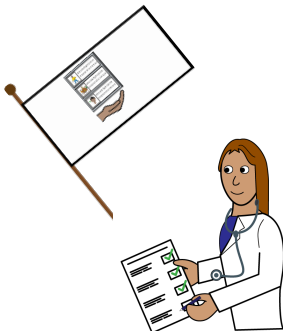
- autistic people and people with learning disabilities should be offered a longer appointment time.



- appointment letters should be written in easy read for those who want it.

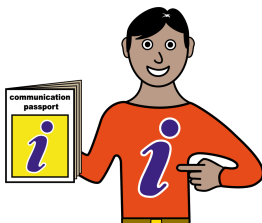


- an easy read patient information section should be available so that everyone can access information.

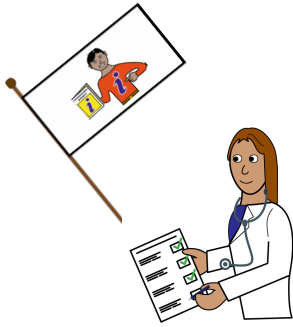


- a flag should be put on patients records to show they need reasonable adjustments.

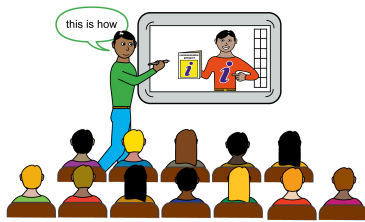
## Health passports



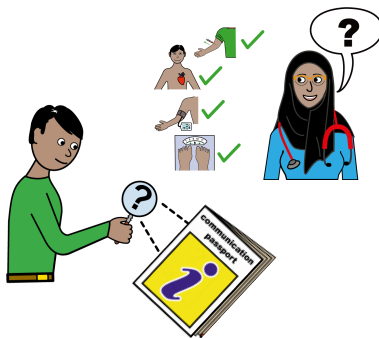
- health passports should be offered to autistic people and people with learning disabilities.



- a flag should be put on patients records to show they have a health passport.

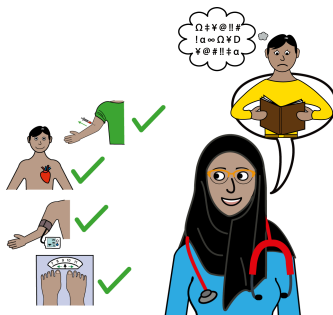


- all healthcare staff should have training on health passports and how to use them.



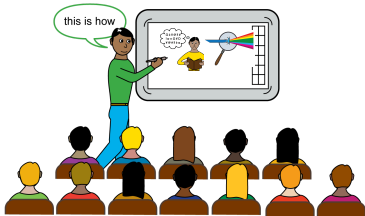
- health passports should be looked at as part of the annual health check.

## Annual health check



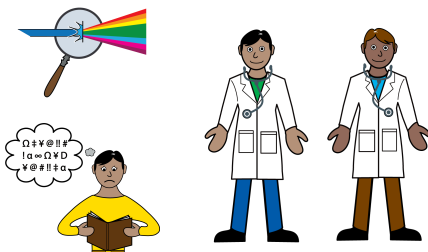
- everyone who should have an annual health check should be offered one.

## Communication & listening

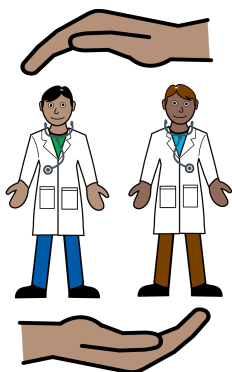


- all healthcare staff should have training on how to talk to autistic people and people with learning disabilities.

## Consistent care



- doctors surgeries to consider giving autistic people and those with learning disabilities 2 named doctors.



These doctors would oversee their care, helping to reduce stress and build relationships and trust.

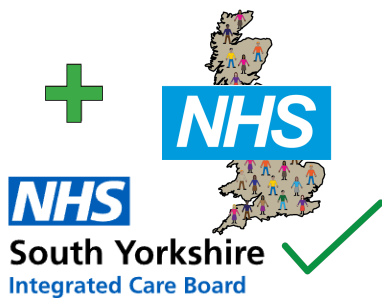
# What did services tell us they were going to do?



We heard back from:

- South Yorkshire ICB
- Rotherham Hospital

## **South Yorkshire ICB response**

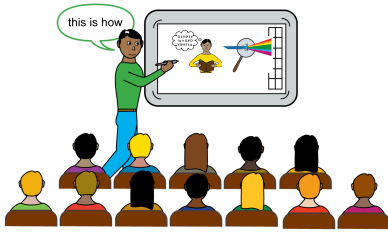


The **South Yorkshire Integrated Care Board (ICB)** is working with NHS England to make improvements.

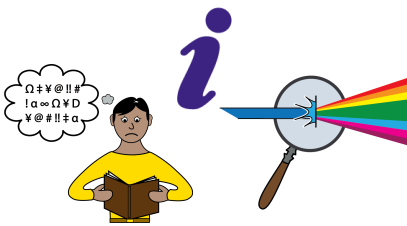


The **South Yorkshire Integrated Care Board (ICB)** is responsible for planning health services for South Yorkshire.

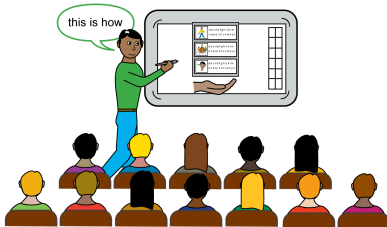
They told us they are:



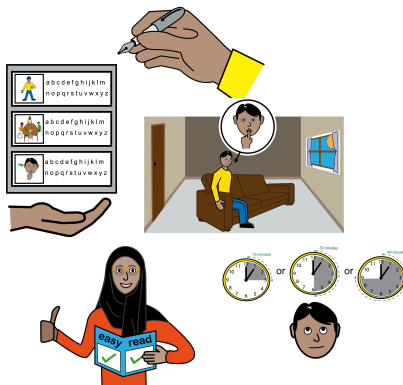
1. Making sure all NHS and social care staff in Rotherham have **Oliver McGowan training**.



**Oliver McGowan training** tells staff about learning disabilities and autism.

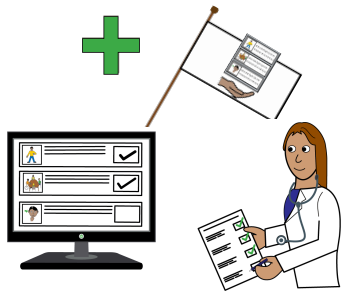


The training gives information about providing reasonable adjustments and how staff can improve communication.

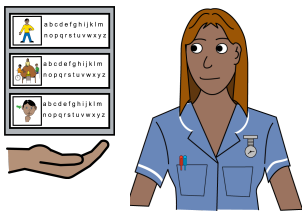


2. Making sure reasonable adjustments are both recorded and provided to patients.

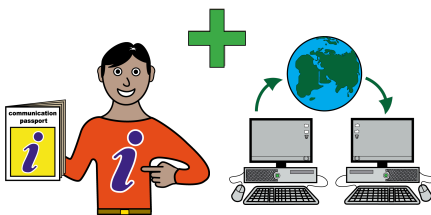




NHS England are working on adding a digital reasonable adjustment flag to patients records.



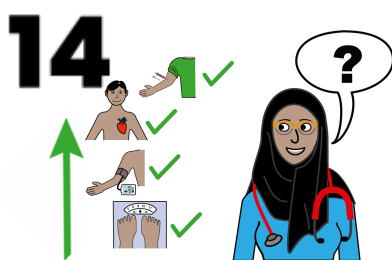
This means healthcare services can see what reasonable adjustments an individual needs.



**3.** Developing their website to encourage more people to use health passports.



South Yorkshire ICB are also working to make health passports better.



**4.** Working to make sure young people aged 14 and over are offered an annual health check.

# Rotherham Hospital's response



Rotherham Hospital follows the **Accessible Information Standard**.



The **Accessible Information Standard** says that everyone should get information in a way they can understand.

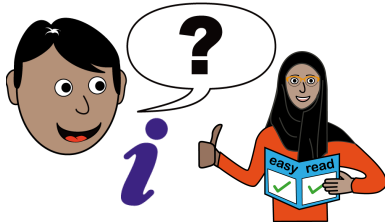
Rotherham Hospital meets this by:



- making their general patient information easier to read by using plain English.



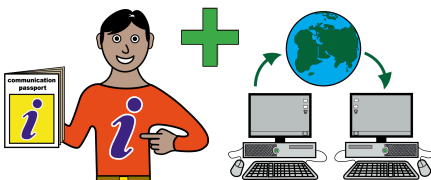
- linking to national organisations who produce easy read information.



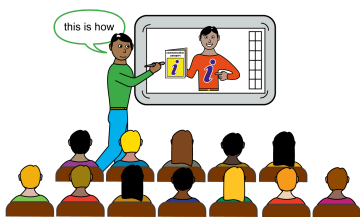
- making information available in easy read to anyone who asks for it.



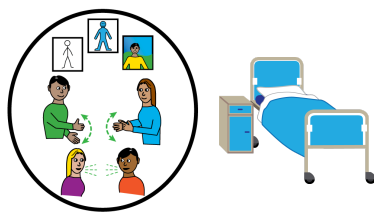
- working to develop easy read appointment letters.



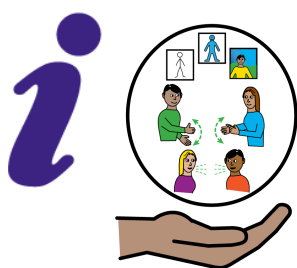
- putting up to date links to all health passports on their website.



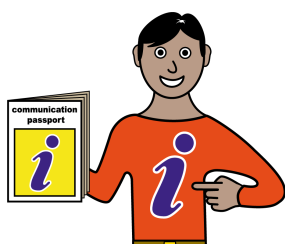
- Promoting the use of hospital passports.



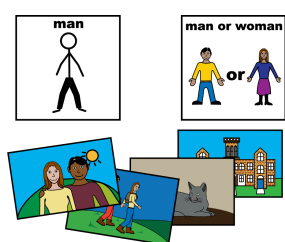
In 2022, Rotherham hospital set up '**Communication stations**' on all wards and in some departments.



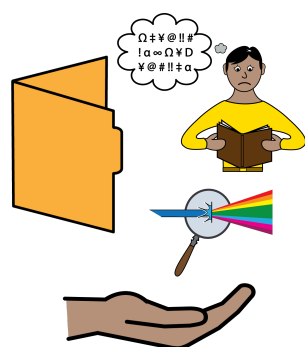
The **Communication Stations** contain helpful information to support people with communication needs such as:



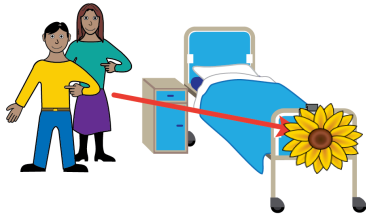
- copies of hospital passports that can be given out.



- picture cards to help communication.



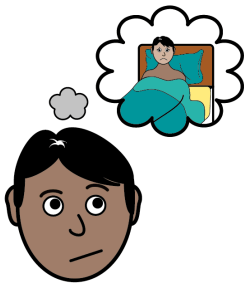
- a folder for staff to read about how to look after autistic people and people with learning disabilities.



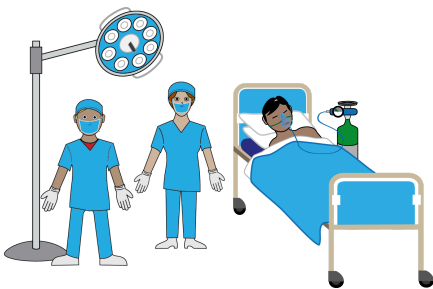
- **Hidden disability sunflowers** which can be put above an inpatients bed name board.



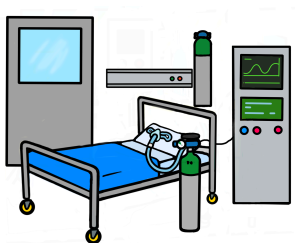
**Hidden disability sunflowers** let staff know they need to look at a patient's record.



Rotherham Hospital helps reduce anxiety for autistic people and people with learning disabilities by:



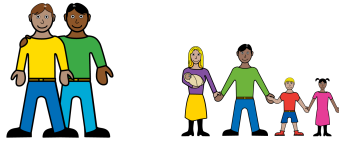
- letting them see the operating theatre before surgery



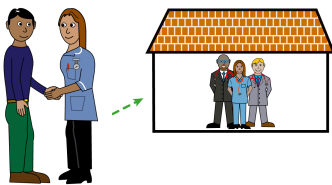
- letting them look at medical equipment before surgery



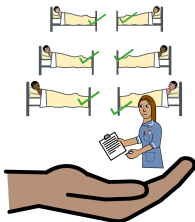
Rotherham Hospital has a learning disability and autism team who can:



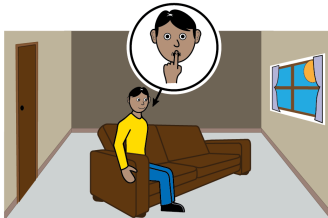
- provide support to patients, carers and staff



- attend appointments with patients



- help provide care on the wards



Rotherham hospital is also looking to provide more quiet space for people to wait in.



## **Dentistry update**

Dental Public Health is working on making some information leaflets in an easy read format.

# Helpful information



Below are some links to give more information about things in this report.



Easy read information can be found on our website:

[healthwatchrotherham.org.uk/easy-read-information](http://healthwatchrotherham.org.uk/easy-read-information)



About the Accessible Information Standard:

[www.england.nhs.uk/wp-content/uploads/2016/07/accessible-info-standard-er-upd-jul16.pdf](http://www.england.nhs.uk/wp-content/uploads/2016/07/accessible-info-standard-er-upd-jul16.pdf)



About reasonable  
adjustments:

[www.mencap.org.uk/easyread/about-reasonable-adjustments](http://www.mencap.org.uk/easyread/about-reasonable-adjustments)



About the learning disability  
register:

[www.mencap.org.uk/easyread/join-the-learning-disability-register](http://www.mencap.org.uk/easyread/join-the-learning-disability-register)

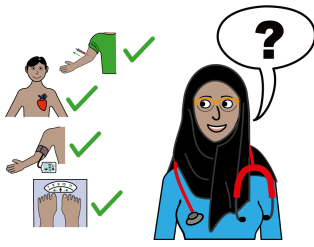
[learningdisabilitymatters.co.uk/annual-health-checks-gp-learning-disability-registers/](http://learningdisabilitymatters.co.uk/annual-health-checks-gp-learning-disability-registers/)



Use this letter to get help at  
the doctors:

[www.mencap.org.uk/resource/download-print-and-complete-letter-ask-support-your-doctors-surgery](http://www.mencap.org.uk/resource/download-print-and-complete-letter-ask-support-your-doctors-surgery)





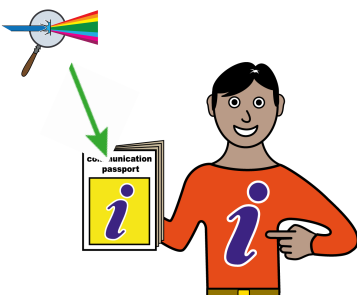
About annual health checks:

[www.mencap.org.uk/easyread/annual-health-checks](http://www.mencap.org.uk/easyread/annual-health-checks)

[learningdisabilitymatters.co.uk/annual-health-checks-gp-learning-disability-registers/](http://learningdisabilitymatters.co.uk/annual-health-checks-gp-learning-disability-registers/)

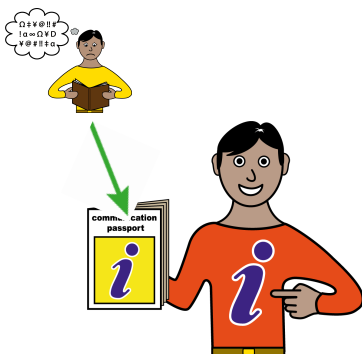
Hospital passport for autistic people:

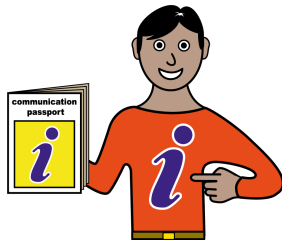
[www.autism.org.uk/advice-and-guidance/topics/physical-health/my-health-passport](http://www.autism.org.uk/advice-and-guidance/topics/physical-health/my-health-passport)



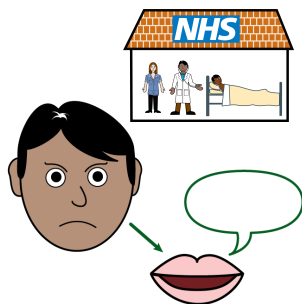
Hospital passport for people with learning disabilities:

[www.mencap.org.uk/advice-and-support/health-coronavirus/health-guides](http://www.mencap.org.uk/advice-and-support/health-coronavirus/health-guides)

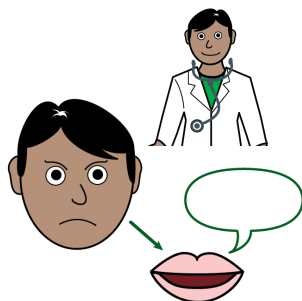




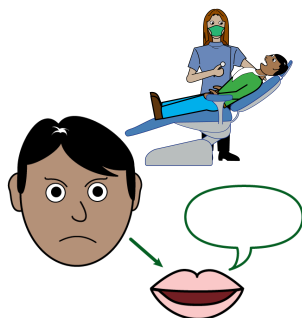
Communication passport:  
[www.changepeople.org/Change/media/Change-Media-Library/Easy%20Blog%20Posts/CHANGE-Communication-Card-v2.pdf](http://www.changepeople.org/Change/media/Change-Media-Library/Easy%20Blog%20Posts/CHANGE-Communication-Card-v2.pdf)



Sorting out problems with your hospital care: [Sorting out problems with your hospital care](#)



Sorting out problems with your care at the doctors: [Sorting out problems with your care at the doctors](#)



Sorting out problems with your care at the dentists: [Sorting out problems with the care at your dentists](#)



Information about what Rotherham hospital does to support autistic people and people with learning difficulties:

<https://www.therotherhamft.nhs.uk/news/rotherham-leads-way-inclusive-healthcare-individuals-autism>



Information about the NHS learning disabilities and autism portfolio team:

[southyorkshire.icb.nhs.uk/your-health/learning-disabilities-and-autism](https://southyorkshire.icb.nhs.uk/your-health/learning-disabilities-and-autism)