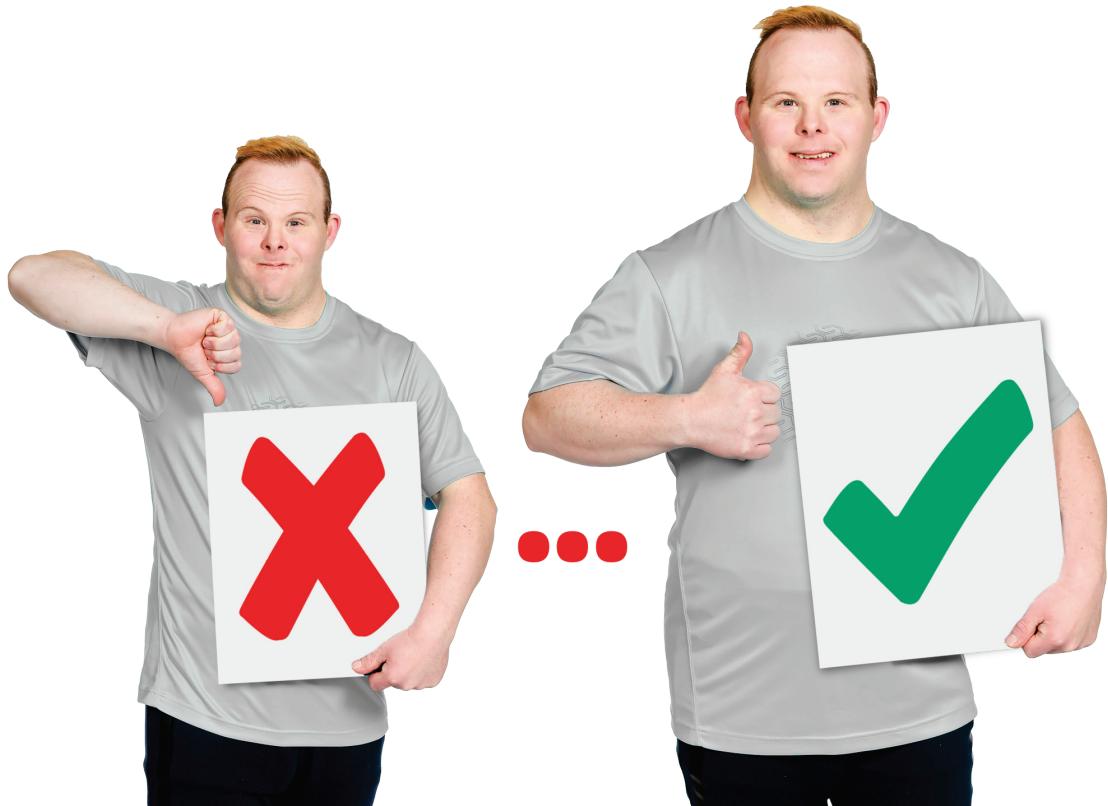




Action from learning report 2020



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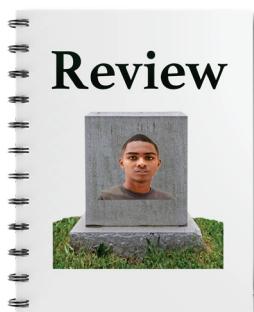


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Welcome



This action from learning easy read report is about the **Learning Disabilities Mortality Review Programme**, which is also called LeDeR.



The **Learning Disability Mortality (death) Review** programme is about making care better for people with a learning disability.



A **LeDeR** review is where the death of a person with a learning disability is looked into to find out more about why they died.



Action from learning means taking what you learn to make good changes.



First thoughts



Three people who work for **NHS England** and **NHS Improvement** told us what they thought about the report.



- | **Ray James** who is National Director of Learning Disability and Autism.



- | **Roger Banks** who is National Clinical Director of Learning Disability and Autism.



- | **Karl Butler** who is a Learning Disability and Autism Adviser in Health Improvement.



Remembering Karl Butler



Karl died suddenly in the last days of June.



We write this **LeDeR Action from Learning report** in memory of Karl.

NHS

Action from learning report 2020



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He worked on this report.



He thought **LeDeR** was very important work.



Karl worked in the NHS for 3 years.

He was a **Learning Disability and Autism Adviser**



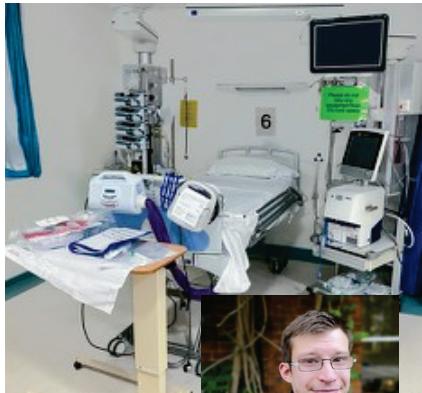
First he worked in the **East of England**.



Then he worked across England in the **national Learning Disability and Autism Team**.



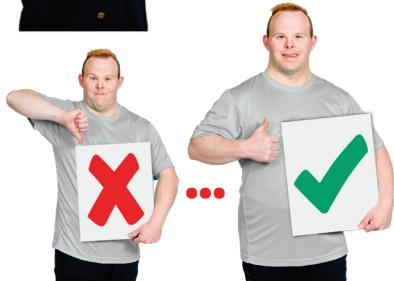
This was his dream!



Karl had a lot of health problems.



He wanted his work at the NHS to make the health of other people with a learning disability better.



He got lots of other people to do this too!



Karl loved music.
His DJ name was KB.



He played the drums and the
cajon, which is he playing in the
picture above.



Karl was a big Manchester United fan.



He loved going to festivals.



He also played a big part in
self advocacy groups.



Karl made us all think about how to make healthcare better.

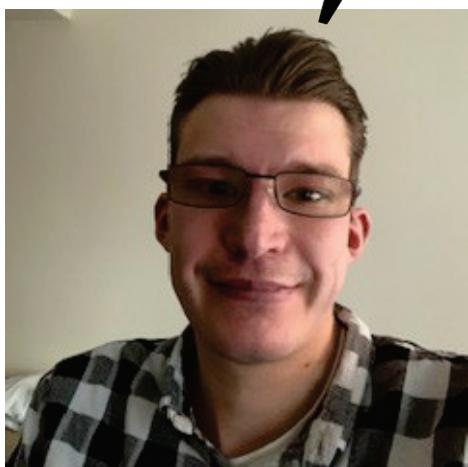
We will keep making healthcare better for autistic people and people with a learning disability.



Here is Karl receiving an award for his work from NHS boss Simon Stevens.

“I am determined to make things right for people so that they can have good, ordinary lives.”

“He lit a fire under everyone he met to make things better.”



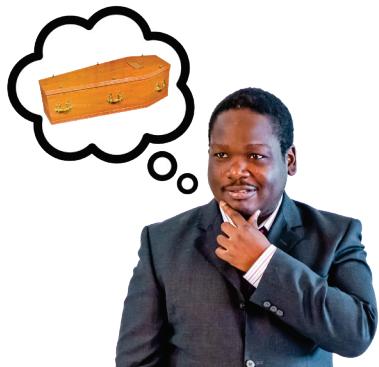


Ray, Roger and Karl said:

"This is the fourth year that we have put out a report on LeDeR.



Too many people with a learning disability are dying earlier than people without a learning disability.



We are learning more about why people die but there is still lots more that needs to be done.



We still need the support of families and carers of people with a learning disability who have died.



This report tells you about things which are happening across England to make things better for people with a learning disability."



In the next year we will **ASK**:



- | people with a learning disability
- | families and carers
- | other organisations
- | and health and care staff

what they think is working well with **LeDeR** and what we need to do differently.



LISTEN to what they tell us.



DO all that we can to make the lives of people with a learning disability better.



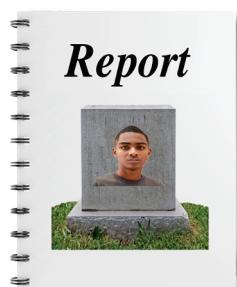
What are we doing?



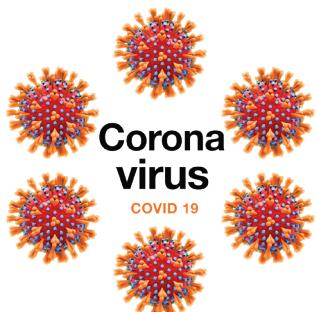
Clinical Commissioning Groups, which are also called CCGs, were given more money to do more reviews.



CCGs are NHS organisations that plan and pay for health services in a local area.



Each CCG has been asked to put out a report about their work on LeDeR.



Because of coronavirus some reports from CCGs have been delayed.



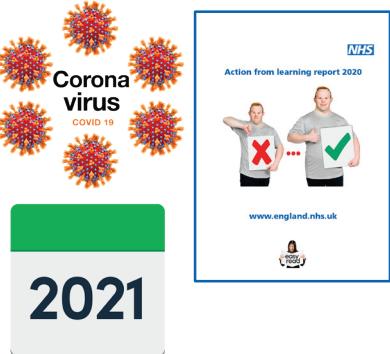
The CCGs have said they will finish their reports by September 2020.



This report is about **LeDeR** work in 2019.



This means that the report **does not** look at what happened to people with a learning disability because of **coronavirus**.



We will say what we have done to support people with a learning disability during **coronavirus** in next year's report.



Nick's story

Nick was a man with a learning disability.



He died in January 2018.



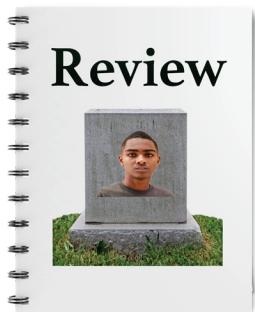
He used **Makaton** and his own signs to speak to others.



He loved horse riding, swimming, holidays, family time and football.



Nick died because he did not get the right food to keep him well.



A LeDeR review about Nick said he might not have died if the people looking after him knew more about



- | eating well



- | weighing him the right way.



In the area Nick lived the NHS made changes to make sure no-one else dies for these reasons.



- | 300 family carers went on training courses about making sure a person with a learning disability eats the food they need



- | Staff were given better information about weighing people who need to sit down or use a wheelchair



- | Staff thought about and changed how they support people with a feeding tube.

Staying well



- | The NHS held a big meeting about staying well for
 - people with a learning disability
 - staff
 - families and carers



- | The local NHS made a new job to support people with a learning disability to eat well and stay healthy.

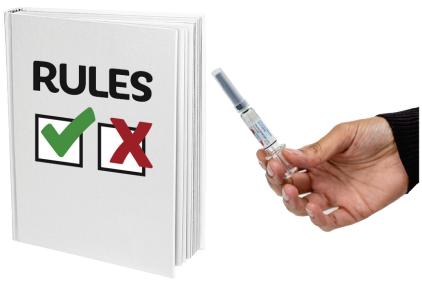
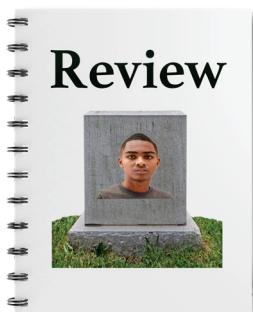


Nick's brother Mark said: "Health professionals need to listen to families and carers more."

They know the person they care for better than anyone else."



What NHS England and NHS Improvement did to make services better



From the reviews we have done, we know that people with a learning disability are dying from:

Pneumonia

Pneumonia is when you have a problem with your lungs and breathing.

This is what we have done to stop people with a learning disability dying from **pneumonia**.

- | we worked with organisations to make sure that people with a learning disability can get the **flu vaccine**.



- | we ran campaigns to make sure people with a learning disability know they can get the fu vaccine.

- | we worked with **Public Health England** to make sure people with a learning disability get the right information

- | we made sure that family carers of people with a learning disability get a free flu jab

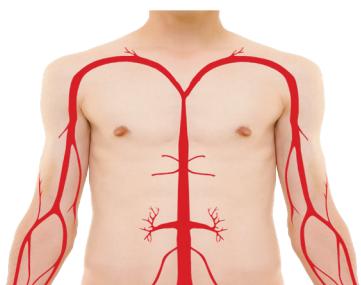
- | We worked with an organisation called the **British Thoracic Society**.

They are a group of doctors, nurses and scientists who know a lot about breathing and lungs.

They helped us write some advice to help make sure that doctors know the best way to care for someone with a learning disability who has pneumonia.



The report will come out later this year.



Sepsis

Sepsis is when you have an infection that gets into your blood and makes you very poorly.



We know that too many people with a learning disability are dying from **sepsis**.

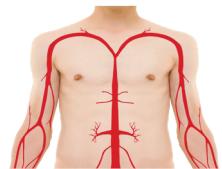
It is really important to know if someone is poorly before they get **sepsis**.



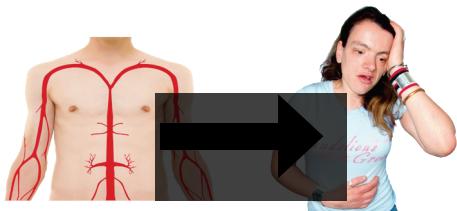
This is what we have done to stop people with a learning disability dying from **sepsis**:



- | we have put out a set of leaflets about
- | how to avoid **sepsis**



| how to spot the signs of sepsis



| problems after sepsis



| we are finding out how technology can help doctors to support people with a learning disability in hospital who are at risk of getting **sepsis**.



Constipation

Constipation is when you find it difficult to poo.



If you find it difficult to poo you can get ill and should see a doctor.

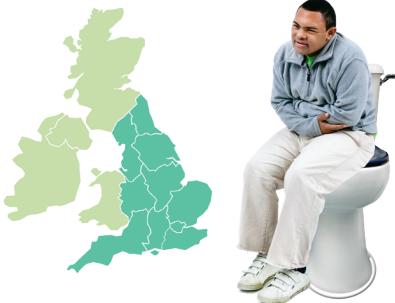
Finding it difficult to poo can be treated.



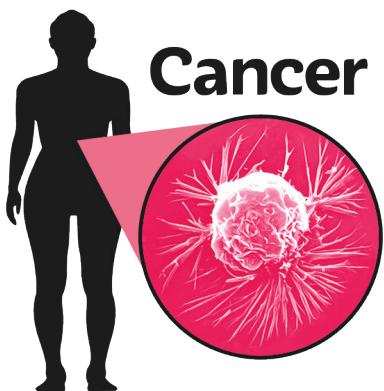
This is what we have done to stop people with a learning disability dying from **constipation**



- | we have written leaflets about constipation for
 - | people with a learning disability
 - | families and carers
 - | healthcare professionals
- | we worked with an organisation called Books Beyond Words to make a book called **The trouble with poo**
 - | to help people with a learning disability understand the risks of constipation
 - | to know when to ask for help



- | we will be running a national campaign to tell people with a learning disability about the risks of constipation.



Cancer

Cancer is a disease that makes your body change. It can cause lumps on your body and make you very poorly.



This is what we have done to stop people with a learning disability dying from **cancer**

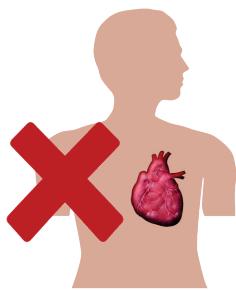


- | we talked to cancer organisations to find ways that **cancer screening** could be easier for people with a learning disability to use

Cancer screening is when you have a check up to see if you might have cancer.



| we are looking at how **reasonable adjustments** can make it easier for people with a learning disability to use **cancer screening services**



Do Not Attempt Cardiopulmonary Resuscitation recommendation or DNACPR



Cardiopulmonary resuscitation or CPR is when someone tries to make your heart start again if it stops.



If people **do not** want to be resuscitated, they can choose to have a **Do Not Attempt Cardiopulmonary Resuscitation recommendation or DNACPR**.



If you have a **Do Not Attempt Cardiopulmonary Resuscitation recommendation** a health professional will not attempt to start your heart if it stops.



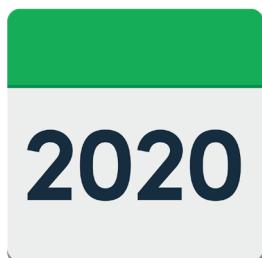
LeDeR reviews tell us that sometimes health professionals do **not** resuscitate someone because they have a learning disability.



Professor Stephen Powis, our national medical director, wrote an urgent letter to NHS staff last year.



In his letter he said that a learning disability should **never** be a reason for not trying to restart someone's heart.



In **2020** we will do more work to make sure



I having a learning disability is never a reason not to resuscitate someone

CERTIFIED COPY OF AN ENTRY OF DEATH
GIVEN AT THE GENERAL REGISTER OFFICE
Application Number: R073054-1

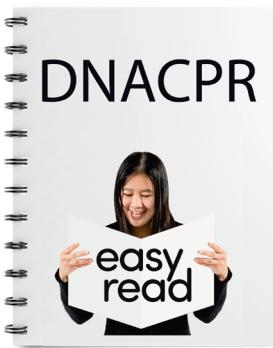
REGISTRATION DISTRICT	GATESHEAD
1954 - GATESHEAD IN THE SUB-DISTRICT OF Whickham	
Name:	John Smith
Date of birth:	12 January 1925
Age:	79 years
Sex:	Male
Marital status:	Married
Years and months:	26 years
Occupation:	Retired
Reason of death:	Stroke
Place of death:	Hospital
Time of death:	10.30 am
Time of registration and issue of certificate:	10.30 am
Where registered:	Gateshead
Signature of Registrar:	[Signature]

CERTIFIED to be a true copy of an entry in the certified copy of a Register of Deaths in the District above named.
Given at the GENERAL REGISTER OFFICE, under the Seal of the Office, this 27th day of February, 2017.

DYB 132068

CAUTION: THERE ARE OFFENCES RELATED TO FALSIFYING OR ALTERING A CERTIFICATE AND IT IS AN OFFENCE TO POSSESS A FAKE CERTIFICATE WHICH COULD BE USED AS EVIDENCE OF DEATH.
MAKING A CERTIFICATE IS NOT EVIDENCE OF DEATH.

I having a learning disability should never be put on a death certificate as the cause of someone's death.



We are going to put out a document about DNACPR in easy read.



Annual health checks



If you have a learning disability you can have a health check up once a year.

This is called an **annual health check**. It makes sure you are well and helps you stay well.



A lot of people with a learning disability do not get their **annual health check**.



We are going to run a campaign in England to get more people to have their **annual health check**.



The campaign has been delayed by coronavirus, but we plan to run it later in 2020.

Medication



This is what we have done to make sure people with a learning disability only take the medication they need and in the amounts they need it.



| The NHS will have more pharmacists who can



support people with a learning disability to get the right medication, at the right time



support people with a learning disability to make choices about medication with their GP



| **a primary care network** is a group of GP surgeries that work closely together with other local health and social care services



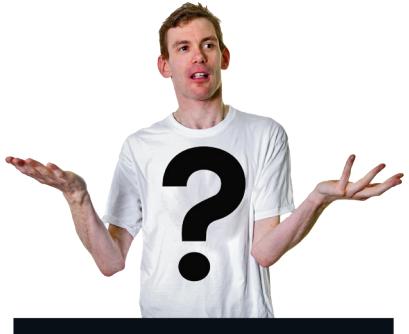
| we are working with **primary care networks** to make sure they



prescribe the right medication



help people with a learning disability to manage their medication better.



What happens next?



In 2020



- | we will ask local **LeDeR** groups to look at the lives of people with a learning disability from **Black, Asian and Minority Ethnic Groups**

Black, Asian and Minority Ethnic Groups are people from different cultures, religions and nationalities.



- | we will work with a new type of doctor who looks at why someone died. These doctors are called **medical examiners**



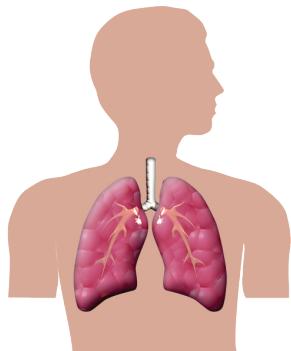
- | we will do more work around the **Mental Capacity Act 2005** to make sure health staff are following the law.



The Mental Capacity Act 2005 makes sure that people get the support they need to make their own choices for as long as possible



- | we will put out information for health and social care staff who support people with a learning disability who are at risk of aspiration pneumonia.



Pneumonia is an infection caused by germs that get into the lungs.



We are going to work with different organisations to



- | provide information for people with a learning disability about stopping, finding and managing pneumonia



- I help people spot when somebody with a learning disability is getting ill, and their illness could get much more serious.



Examples of local areas that are making a difference

Eating well in Gloucestershire



Learning disability teams in Gloucestershire have given staff the right equipment and training to make sure that people with a learning disability have a good diet and are staying healthy.



The staff are learning

| how much food is right for each person



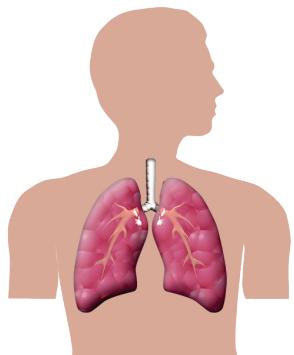
| to make sure that people eat the type of food they need



| about meal planning.



The teams have also made sure that staff know how to weigh and measure people with a learning disability.



Looking after your lungs



In the North West, the self-advocacy group **People First Merseyside**, ran a lung health campaign.



The campaign included a booklet with advice on

- | breathing well
- | how to live well
- | tips on healthy eating
- | breathing exercises.



Dysphagia training

Lots of people with a learning disability have problems swallowing. This is called **dysphagia**.



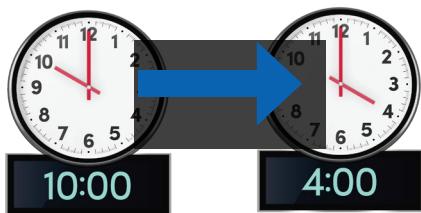
In Hertfordshire they offered free training about **dysphagia** to family carers of people with a learning disability that have **dysphagia**.



The feedback about the training was good and



- | the number of courses every year has increased from 4 to 6



- | the courses are now **all day**, before they were half a day.



Stopping people from going to hospital



Cheshire and Wirral Partnership NHS Foundation Trust's community learning disability team wrote a guide to help them work out when people with a learning disability are at risk of going into hospital.

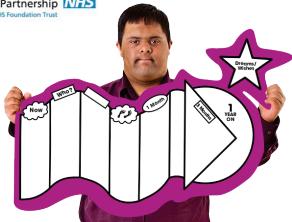


Once they know a person with a learning disability might need to go to hospital they get a **person-centred care plan** that helps to stop them from going into hospital.

Constipation



The work that Cheshire and Wirral NHS Foundation Trust is doing



- | makes sure people with a learning disability have a person-centred care plan if they have constipation



- | makes staff training about constipation better

- | makes staff more aware about how serious constipation can be

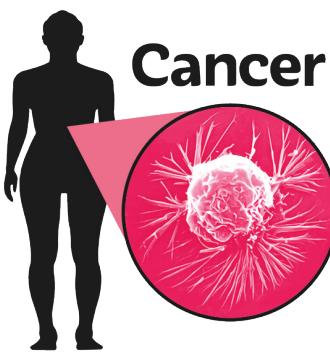


- | makes videos to help everyone understand

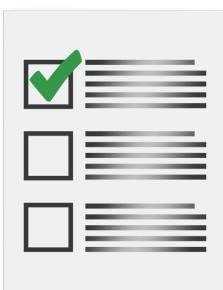
how serious constipation is

how to spot the early signs of constipation.





Cancer



The North East and Cumbria Learning Disability Network have made a check list.

The check list works out if services have made it easier for people with a learning disability to use **cancer screening**.



They have worked with an organisation called **Skills for People** to employ people with a learning disability.



They visit screening centres to see if the service could be better.



Epilepsy



Alder Hey Children's NHS Foundation Trust has a new job called a learning disability epilepsy specialist nurse.



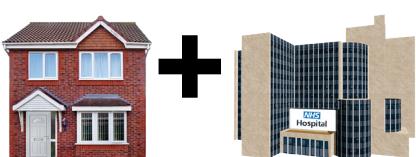
The nurse will support

- | children
- | young people
- | their families and carers.



The nurse will look at things like

- | taking medication
- | positive behaviour support needs.



The nurse will work closely with children and young people at home and at the hospital.



Digital flag



In Gloucestershire and Devon staff are making sure they use the reasonable adjustments note on computers - call the **digital flag**.



The **digital flag** tells medical staff if someone has a learning disability, autism or both, so they can

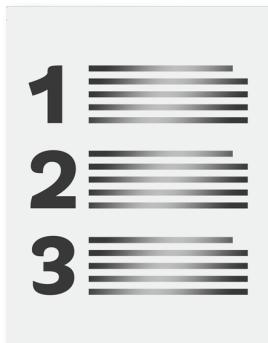


- | make it easier for a person with a learning disability to use health services

- | make visits to the hospital more positive.



Reasonable adjustments

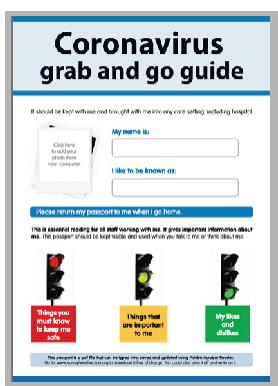


Sussex Transforming Care Partnership has updated their 'All About Me Passport'.

The passport lists the last 3 times a person with a learning disability had to stay in hospital.

This gives hospital staff the information they need to support the person in hospital.

Because of coronavirus the NHS has also made a shorter hospital passport called a **coronavirus grab and go guide**





Annual health checks

Over the past 2 years



NHS North Lincolnshire CCG

and



NHS Rotherham, Doncaster and South Humber Community Learning Disability Team



have done lots of work to make sure that people are on the **GP learning disability register** so that they get their annual health checks.



The number of people on the **GP learning disability register** has gone up from **577** to **891**.



Find out more about our work



The University of Bristol work with us on the LeDeR programme.



You can find out more about their work at

www.bristol.ac.uk/sps/leder



You can find out more about the NHS England and NHS Improvement learning disability and autism programme at

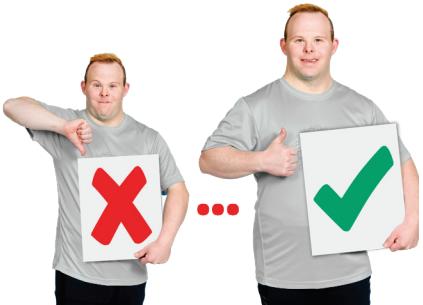
www.england.nhs.uk/learning-disabilities



Thank you



| for sharing your stories with us



| for your hard work in helping us to make services better for people with a learning disability.



**Camden People First for
helping us write this easy read report.**

This EasyRead booklet was produced by
www.easy-read-documents.com

