



Action From Learning **LeDeR Report** 2021 – 2022

What's inside?



NHS

What is LeDeR?



When a person with a learning disability dies, a LeDeR review looks at the health and social care the person received.



LeDeR is about learning from lives and deaths of people with a learning disability and autistic people.



From early in 2022 LeDeR reviews began to look at the deaths of autistic people.

What is LeDeR?



This document is the **Action from Learning** easy read report which explains what we have learned from all the **LeDeR reviews**.



Action from learning means learning from **LeDeR reviews** to make the right changes so that people live longer and healthier lives.

We want to say 'thank you' to



- Families and health and care workers who have taken part in a **LeDeR review**



- Families who have shared their **memories** and **experiences** in this report



- **Health and care workers** who have made the lives of people with a learning disability and autistic people better in the last year.

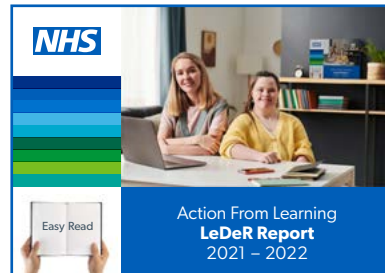
NHS



First thoughts



Every death of a person with a learning disability or an autistic person is sad.



This report will tell you about the good changes we have made because of what we have learned.



So that people can live happier and healthier lives.





First thoughts



In this section you can read what three people who work for **NHS England** think about **LeDeR**.

Tom's thoughts



Tom Cahill is the National Director for Learning Disability and Autism.



"People with a learning disability and autistic people are still dying too young."

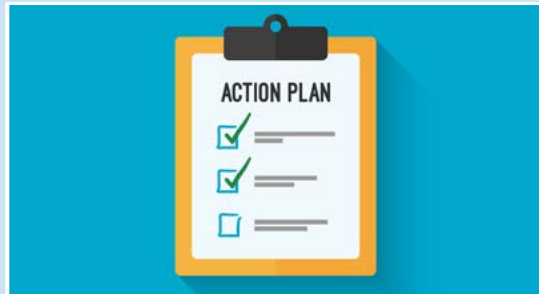




First thoughts



“LeDeR reviews show us what needs to change.”



“I will work to make sure health services learn from LeDeR reviews and do things better.”



“This report shows how working together can lead to people with a learning disability and autistic people living better and healthier lives.”





First thoughts

Roger's thoughts



Dr Roger Banks is the National Clinical Director for Learning Disability and Autism.



"It is important that people are more involved in their care."



"We know that coronavirus has had a big effect on people."





First thoughts



"This makes the **NHS** want to do much more to make care better."



"This year we have started to look more closely at the lives and deaths of people from **minority ethnic groups.**"



"**Minority ethnic groups** means people who are not White British."



First thoughts



“The **NHS** is making sure that reasonable adjustments are made for everyone who needs them.”



“**Reasonable adjustments** means making it easier for disabled people to use the **NHS**.”

NHS



First thoughts

Carl's thoughts



Carl Shaw is a Learning Disability and Autism Adviser

NHS

NHS
England

"I work as a learning disability and autism adviser for **NHS England.**"



"I think it is really important that LeDeR reviews are now being done for autistic people."

First thoughts



“Over the next year I would like healthcare professionals to learn more about the different needs of:



- people with a learning disability
- autistic people.”

Andrew's story



A new video has been produced in the North East of England after a LeDeR review.

Go to YouTube and search for **See Me Andrew's Story**



The video tells health and social care staff and everyone else to:

- listen to people with a learning disability



- question their ideas about doing the right thing for people with a learning disability.



Andrew's story



The video is about the experiences of Andrew who died in early 2020.



The film was produced by the local drama group MiXiT.



Andrew was 51 but was very frail and he lived with Down's syndrome.

Andrew's story



Andrew went into hospital with a very bad urine infection.



He was not getting better from the urine infection and staff did not find out why he was still ill.



Staff thought Andrew was acting differently because of his dementia and learning disability.

NHS



Andrew's story



So staff did not work out that he had two broken hips.



County Durham Clinical Commissioning Group and **County Durham and Darlington NHS Foundation Trust** are sharing Andrew's story to show that:



- reasonable adjustments should be made for people with a learning disability and autistic people



- no-one should assume how autistic people and people with a learning disability behave.





Andrew's story



Andrew's family agreed for the video to be made.



His family hope Andrew's story will change how health and care staff think about people with a learning disability and autistic people.



The video was made to be Andrew's voice because he could not speak when he was alive.



Andrew's story



The video was made to help people understand how to:

- see the person, not their learning disability or autism
- ask the right questions
- look out for problems so they do not get missed.

NHS

Safe and wellbeing reviews



Extra checks were made last winter on people with a learning disability and autistic people in mental health hospitals.



The checks made sure:

- people were safe and well
- any safety concerns were sorted out in the right way.



The information found from the checks is being used to make services better for people with a learning disability and autistic people.

LeDeR champions

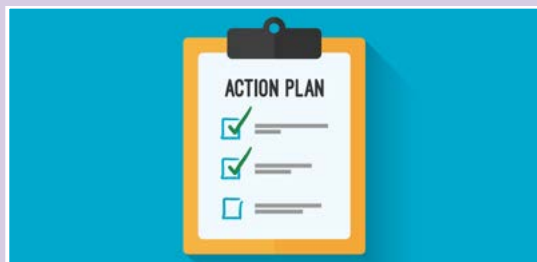


Every area in England will have a **LeDeR champion**.



The **LeDeR champions** in the areas across England will:

- check that the **NHS** is making care better for people with a learning disability and autistic people



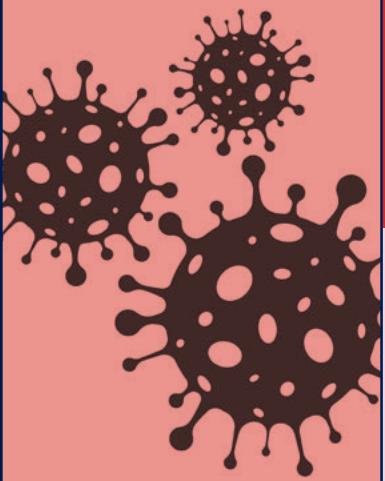
- take action if they do not think services are getting better.



The **LeDeR champions** also have to tell us what they are doing to **make care better** for people from **minority ethnic groups**.

NHS

Coronavirus



COVID-19
Coronavirus



People with a learning disability are more at risk of becoming seriously unwell if they get **coronavirus**.

NHS

 **COVID-19**
Coronavirus



The **NHS** has found a lot of new ways to support vulnerable people with **coronavirus**.

Coronavirus

COVID-19
Coronavirus

NHS

NHS

In the last year the **NHS**:



- made sure that people with a learning disability could have **coronavirus** vaccines sooner than other people



- made lots of films and other types of information about **coronavirus** vaccines



There are two ways
to request vaccine
status

NHS
COVID Vaccine



Download the NHS App, this is the easiest and most convenient way. You can also get a paper copy of your vaccine status by downloading a PDF straight from the app.



Call 119 and request a paper letter from the NHS. You should receive one in five working days. Only call if you have less than four weeks until you travel.

- made sure that invitations for **coronavirus** vaccines were easy to understand

Coronavirus

COVID-19
Coronavirus

NHS



- helped to make the coronavirus vaccine booking service easy to use



- helped to train staff so that everyone has a good experience when they go for their coronavirus vaccine

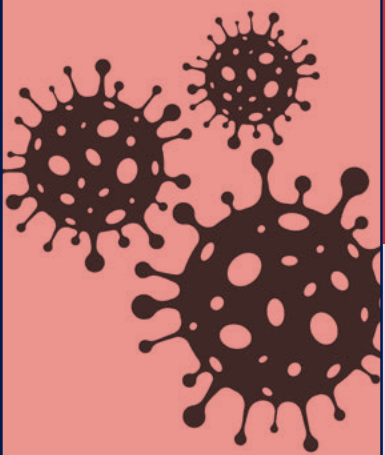


- worked with **Misfits Theatre company** to make a film about how **important** it is for people with a **learning disability** to get the vaccine.

 YouTube

Go to YouTube and search for '**Misfits vaccine NHS**'

Coronavirus



COVID-19
Coronavirus

NHS

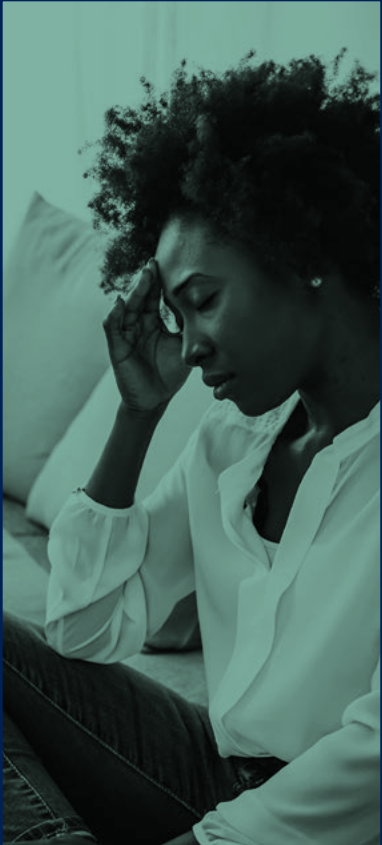


- made sure that people who **could not** go to a **vaccine centre** could still get their vaccine:
 - **at home**
 - at a place **better suited** to their **needs**

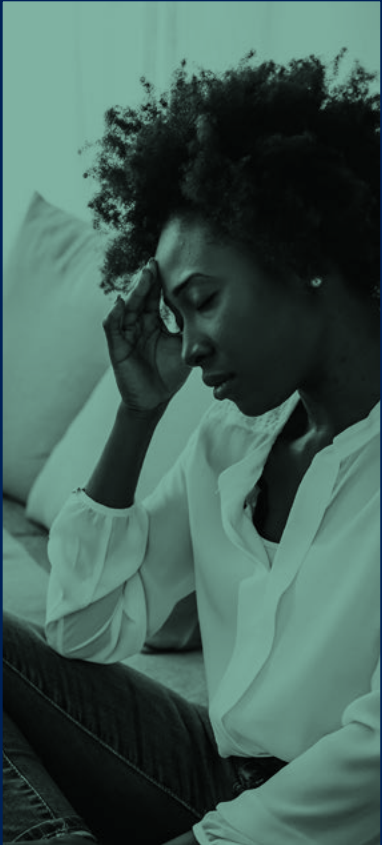


- made sure that people who are at high risk of becoming seriously unwell from coronavirus could get new treatments.

Managing health problems



NHS



NHS

Breathing problems



Breathing problems cause a lot of people with a **learning disability** to die too soon.



There is a health problem called **dysphagia** which **lots** of people with a **learning disability** have.

It means you find it **difficult to swallow** and can **affect** your **breathing**.



Food or other things can get in your **lungs** if you have **problems swallowing** and lead to an **infection** called **aspiration pneumonia**.



Breathing problems



A guide on **pneumonia** and **aspiration pneumonia** was written by the **British Thoracic Society**.



British
Thoracic
Society



The **British Thoracic Society** is a team of:

- **doctors**
- **nurses**
- **scientists.**



The team worked with people with a learning disability and their families.

NHS

Breathing problems



The **NHS** is also writing information to help healthcare staff so they can:



- stop people getting pneumonia
- give people the right treatment.



Hospitals will get extra money for treating people with pneumonia properly.



Flu vaccines



Flu vaccines are still **very important** for people with a learning disability.

NHS



LeDeR reviews say people with a learning disability sometimes **miss out** on treatments such as **flu vaccines** which help to **stop serious illness**.

Flu Vaccines



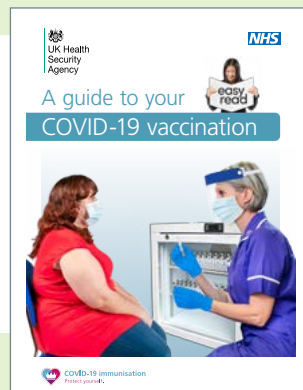
What the NHS has done this year



Supported people to get their **flu vaccine** at the same time as their **coronavirus vaccine**.



By February 2022 the flu vaccine had been given to 3 out of every 4 people with a learning disability who needed it.

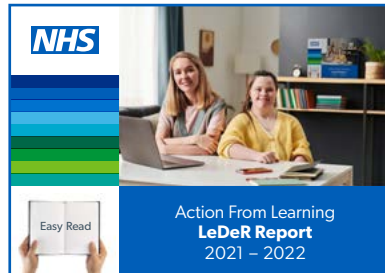


Updated information about the vaccine.

Gave **doctors (GPs)** an **easy read letter** to **invite** people to get their vaccine.



Noticing when someone is becoming very unwell



LeDeR reviews have told us that:



- **families** and **carers** can tell when the person they care for is getting **more unwell**



- families and carers **need to know** how to **quickly** get the **right help** for the person they care for.



Noticing when someone is becoming very unwell



The **NHS** has worked with:



Royal College
of Physicians

- The Royal College of Physicians



- The Society for Acute Medicine.



Both organisations are groups of doctors, nurses and scientists.





Noticing when someone is becoming very unwell

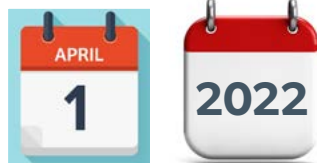


We asked **both organisations** to make a document for healthcare professionals who:

- work in hospitals



- give emergency care to people with a learning disability.



The Royal College of Physicians put this document out on **1 April 2022**.

NHS

Constipation



Constipation is when you find it **difficult to poo**.



Some people with a **learning disability** are **more likely** to have problems with **constipation**.



People with a learning disability are **often** given **medicine** to treat constipation.

Constipation



There is a project to tell people more about constipation.



The project will help people understand how to:



- treat constipation



- stop someone getting constipated



- find out if someone is constipated.

Cancer



People with a learning disability are **less likely to die of cancer.**



But **LeDeR reviews** found out that it takes a **long time** for people with a learning disability to **find out** if they have **cancer.**



One of the reasons for this is that **a lot** of people with a learning disability **do not get cancer screenings.**

Cancer



What the NHS did in the last year:



- put out **new information** about **cancer screening**



This information explained how the **NHS** can make **breast cancer** services **easier** for everyone to use.

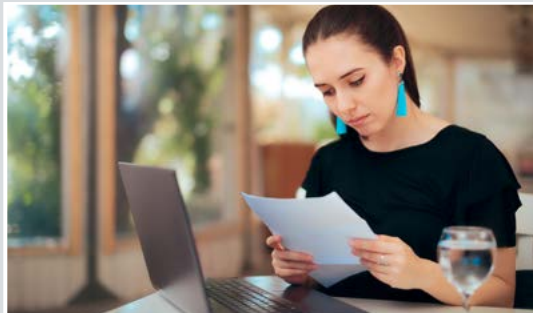


www.mencap.org.uk/advice-and-support/health-coronavirus/cancer-screening

Cancer



- asked doctors (GPs) who is on their **learning disability register** so that the cancer screening programme has **this information**



- looked at the **invites** and **follow up letters** from the **NHS** cancer screening services to make sure they are **easy to understand**



- gave doctors (GPs) **new information** to make sure autistic people and people with a learning disability have their **cancer screening**.

Cancer



- made sure that **NHS** information about cancer screening on the television and internet is:
 - easy to understand
 - includes people with a learning disability



- offered lung screening for some people who used to smoke to see if they might have lung cancer

NHS

Cancer



- made sure that **surveys** about **patient care** are easy to understand



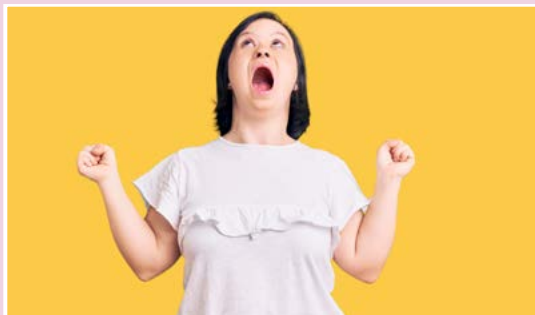
- worked with **Prostate Cancer UK** and checked their easy read information.

NHS

Epilepsy



Epilepsy is a condition that affects the **brain** and causes **seizures**.



Seizures can change how a person:

- **behaves**
- **moves**
- **feels.**



Lots of people with a learning disability have seizures.

Epilepsy



SUDEP Action are a charity that gives advice on how to **stop** people **dying too young** from **epilepsy**.



SUDEP Action has a safety checklist which you can watch as a video on their website

sudep.org/checklist



The **NHS** gave **money** to **SUDEP Action** to make the checklist easier to understand.

NHS

Epilepsy



The **NHS** has been working with **NICE** on **new guidelines** for finding and managing **epilepsy**.



NICE

National Institute for
Health and Care Excellence

NICE is short for the **National Institute** for **Health** and **Care** **Excellence**.



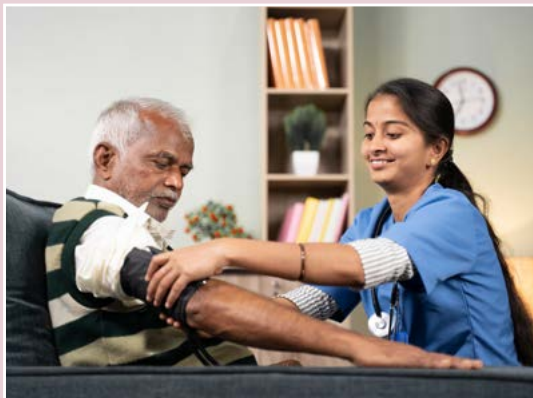
NICE find out what **works well** in health and social care and comes up with guidelines and advice.

Annual health checks



The **NHS** wants **everyone with a** learning disability who wants an **annual health check** to have one.

NHS



Annual health checks can find health issues **before** they become a **big problem**.

Annual health checks



We know that lots of **good work** was done **across the country** because many more people had an **annual health check** last year.



We are making sure that people with a learning disability who are in **prison for longer than a year** can also get an **annual health check**.

Image source:

<https://www.nao.org.uk/report/mental-health-in-prisons/>

NHS

The health of people from minority ethnic groups



LeDeR tells us that people from **minority ethnic groups** with a learning disability **die younger** than **white people**.



We know that **not everybody** from minority ethnic groups is on their **GP learning disability register**.

The health of people from minority ethnic groups



We are working with other organisations to **change this**.



The **NHS** have employed someone to make sure **more people** from minority ethnic groups get the **right care** at the **right time**.

The health of people from minority ethnic groups



The **NHS** are working with three organisations to help us understand how to make **health care better** for people from **minority ethnic groups** with a learning disability.



The three organisations are:

- Learning Disability England
- The Race Equality Foundation
- and The NHS Race and Health Observatory.



This work looks at:

- how the **NHS** works with people, families and carers
- how local areas can support people to be treated fairly.

The health of people from minority ethnic groups



A **report** on this work will **come** out later in **2022**.



The **NHS Race and Health Observatory** is finding out **how** people from minority ethnic groups **get healthcare**.



The **NHS Race and Health Observatory** carries out research to find out if minority ethnic groups get a different health and care service to everyone else

The health of people from minority ethnic groups



Local areas are working to understand **how many** LeDeR reviews there should be about people from **different minority ethnic groups** in their **area**.



Local areas need to have a **plan** to **make sure** that people from minority ethnic groups get the **same level of care** as other people.

NHS

Do Not Attempt Cardiopulmonary Resuscitation or DNACPR



Cardiopulmonary resuscitation or **CPR** is when someone tries to make a person's **heart start again** if it **stops**.



DNACPR is short for **Do Not Attempt Cardiopulmonary Resuscitation**.

DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION (DNACPR)
Valid for up to 12 months and can be renewed on expiry or previously. Once the order expires or is cancelled, the patient will be eligible for all other appropriate treatment and care will be provided.

East of England
NHS
DO NOT PHOTOCOPY

Name: _____
Address: _____
Date of DNACPR order: _____

Reason for DNACPR decision (tick one or more boxes and provide further information):
 CPR is unlikely to be successful as a medically futile because:
 Successful CPR is likely to result in a length and quality of life in the best interests of the patient because:
 Patient does not seem to be resuscitated as indicated by:

RECORD OF DISCUSSION OF DECISION (tick each box and provide further information):
Discussed with the patient (or their Proxy or Attorney, if applicable)? Yes No
If you record consent or discussion, if 'no' say why not discussed:
Discussed with relatives / patient (where)? Yes No
If you record consent, relationship to patient and content of discussion, if 'no' say why not discussed:
Discussed with other members of the health care team? Yes No
If you record notes, date and content of discussion, if 'no' say why not discussed:

Is DNACPR decision indicated? Yes No If 'no' specify reason date: _____

HEALTHCARE PROFESSIONAL COMPLETING THIS DNACPR ORDER
Name: _____
Position: _____

REVIEW AND ENDORSEMENT BY RESPONSIBLE SENIOR CLINICIAN
Name: _____
Position: _____

If people **do not** want to be resuscitated, they can choose to have a **DNACPR**.

This means a health professional **will not** try to start their heart again if it stops.



Do Not Attempt Cardiopulmonary Resuscitation or DNACPR



A **decision** about DNACPR is a personal choice and must only be made by talking to **the person**.

In some cases their **family or carers might be** involved in the decision.

The **NHS** is doing **more work** to make sure that **DNACPRs** are put in place correctly and matches the persons own choices.

Reasonable adjustments

Digital flag



The **NHS** wants more information about **reasonable adjustments** on the electronic records for people with a learning disability and autistic people.



This is called a **digital flag** and can **help medical staff** to:

- make sure services are easier to use



- make hospital visits a **better experience**.

Reasonable adjustments



Before all of the **NHS** starts using the **new digital flag** a group of organisations will try it out over the next year to see **how well** it works.

NHS

Misfits film



We asked **Misfits Theatre Company** to make a film about reasonable adjustments for healthcare professionals.



Go to www.youtube.com and search for 'reasonable adjustments nhs'

<https://www.youtube.com/watch?v=IQynWG4LCnw>

Medication



Psychotropic medicine is medicine that can change your:

- thoughts, mood, feelings
- the way you behave.

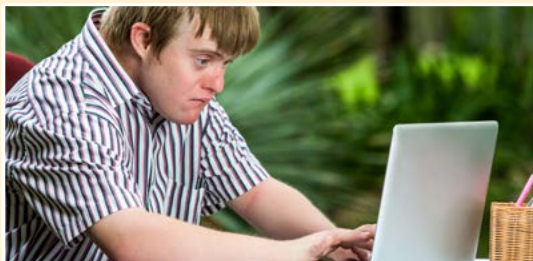


This medicine is given for different reasons such as:

- mental health conditions
- sleep problems
- epilepsy.

NHS

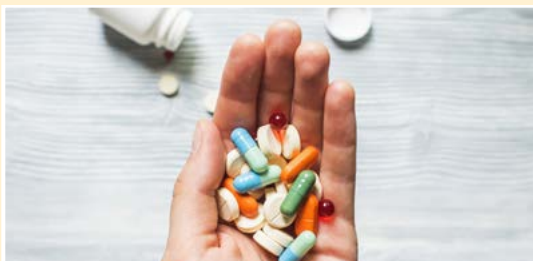
Medication



People with a learning disability and autistic people are **more likely** to be given these **medications**.



Sometimes people are given **medication** to change their **behaviour**.



Sometimes people with a learning disability are given **too much medication**.



Sometimes people with a learning disability take the **medication for a long time**.

NHS

Medication



A big campaign called **STOMP-STAMP** is trying to make sure that people get:

- the right medication at the right time
- only when they need it.



The campaign is looking at **other ways to support** people who take **psychotropic medication**.

The NHS logo, consisting of the letters 'NHS' in white on a blue rectangular background.

Medication



We have worked with the **National Autistic Society** to make **STOMP** information for autistic people and their families that explains:



- psychotropic medicine



- medication reviews.

LeDeR promise



In the next year the LeDeR team will:




1. Work with people who run:

- cancer screening services
- and
- cancer treatment services



to make these services better for people with a learning disability and autistic people

LeDeR promise



The image shows a red-bordered NHS form titled 'DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION (DNACPR)'. It is for the East of England region. The form includes fields for Name, Address, NHS number, and Date of DNACPR order. It also contains sections for 'REASON FOR DNACPR DECISION', 'RECORD OF DISCUSSION OF DNACPR', and 'HEALTHCARE PROFESSIONAL COMPLETING THIS DNACPR ORDER'. The form is marked with a red border and a 'DO NOT PROCEED' stamp.

2. Check that DNACPR forms are being completed correctly



3. Support local services to use the new NHS information pack on breathing problems



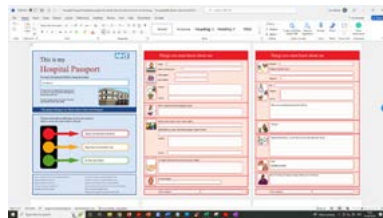
so that care for people with a learning disability and autistic people will get better.



LeDeR promise



4. Find out why people with a learning disability and autistic people are more likely to:
- get high blood pressure and
 - have problems with their heart or blood vessels.



5. Find out if putting hospital passports on mobile phones or computers makes them easier to use

NHS

LeDeR promise



6. Work with other organisations to train more carers and staff so they can quickly notice



when a person with a learning disability or an autistic person becomes unwell.

The NHS logo, consisting of the letters 'NHS' in white on a blue rectangular background.

LeDeR promise



7. Make an information pack about using CPAP machines for:



- people with a learning disability
- autistic people
- their carers.



A CPAP machine helps people to breathe while they are asleep.

LeDeR promise



8. Start a social media campaign to give these groups useful information on preventing and treating constipation:

NHS



- people with a learning disability
- autistic people
- carers
- health professionals.

Find out more



You can find out more about:
the **NHS England LeDeR** programme at
leder.nhs.uk/

NHS
England

The **NHS England** learning disability and autism
programme at
www.england.nhs.uk/learning-disabilities



This document was made in
July 2022