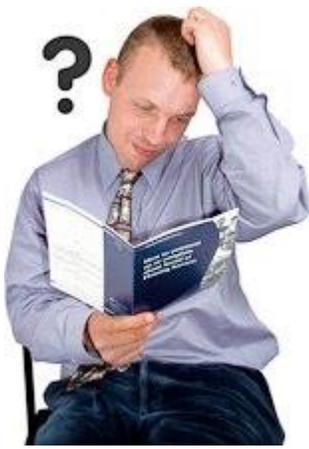


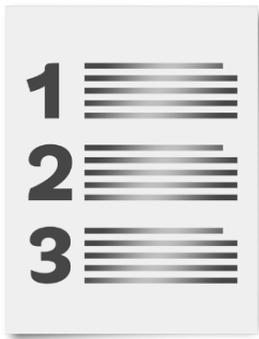
We deserve better: Ethnicity and difference in health and care

Easy Read report

July 2023



Here are some useful words that will help you understand this report...



Policy

A policy is written by the government and tells services what to do



Research

Scientists write articles to tell people about the work they do, this is called research



LeDeR

A project about learning from the deaths of people with a learning disability and autistic people



Racism

Being treated unfairly or badly because of your ethnicity or skin colour



This report looks at people with a **learning disability** who are from **ethnic minority backgrounds**



What we mean by **ethnicity** can be hard to explain



Sometimes people say ethnicity describes things like **where your family are originally from** or your **religion**

“Black”



Sometimes words like **Black** are used to describe people who are from Africa and the Caribbean

“Asian”



Sometimes **Asian** is used to describe people who are from India, Pakistan and other places in Asia



In Britain, a lot of the time people say you are from an **ethnic minority** if your family was originally from the Caribbean, Africa or Asia



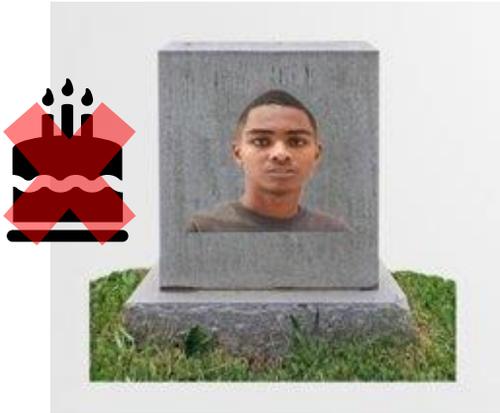
People with a learning disability may **die at a younger age** than people without a learning disability



People with a learning disability may have **more health problems** than people without a learning disability



It is even **worse** for people with a learning disability who are from **ethnic minority backgrounds**



They may die **even younger** than white people with a learning disability



They may have **more problems** with their care



We wanted to find out **why**, so we looked at three different problems

We looked at...



Problems **getting help** when you need it – like getting appointments with a doctor



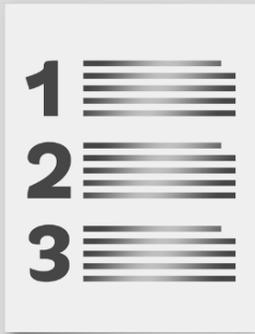
Problems with **what your care is like** – like if you feel your doctor understands you and looks after you well



Problems with your **health** – like dying at a younger age or getting sick

The report has 5 parts

Each part has a different colour



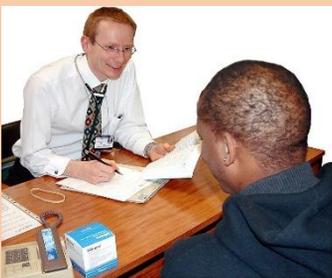
1. What do **policies** tell us?



2. What does other **research** tell us?



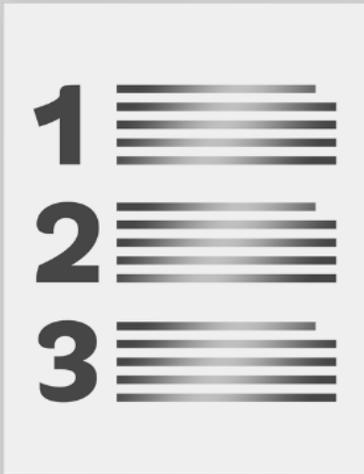
3. What do **people** with lived experience tell us?



4. Do **doctors** know enough about your ethnicity?



5. What does **LeDeR** tell us?



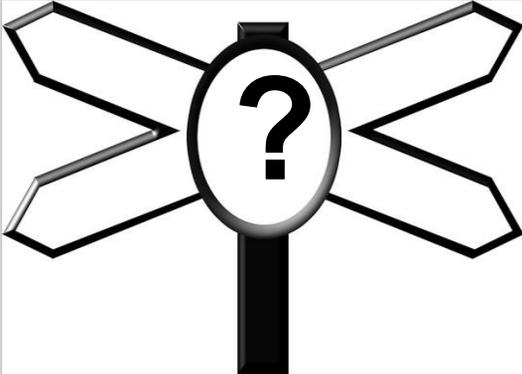
The first part of the report is about **policies**



Policies are written by the government to tell services (doctors, hospitals) what they should do to support people



We found there are **not enough policies** about people with a learning disability from ethnic minorities



Services do not have **clear advice** from government



This makes it **harder** to make things better for people



We need more policies about people with a learning disability from ethnic minorities



The second part of our report is about what **we already know from research**



We looked at lots of research about people with a learning disability from ethnic minority backgrounds



There was not enough research looking at **physical health** problems



There was more research looking at **mental health** problems, but still not enough



We found lots of research looked at people who are '**South Asian**'



Very little research looks at people from other ethnic minorities



We found scientists use **big groups** to talk about people from ethnic minorities



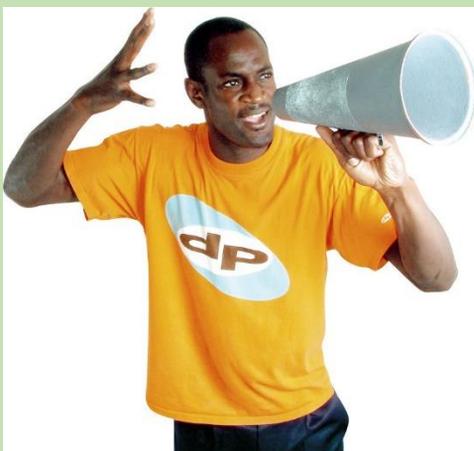
It can be useful to use big groups like 'Asian' to look at how racism causes people to have bad experiences



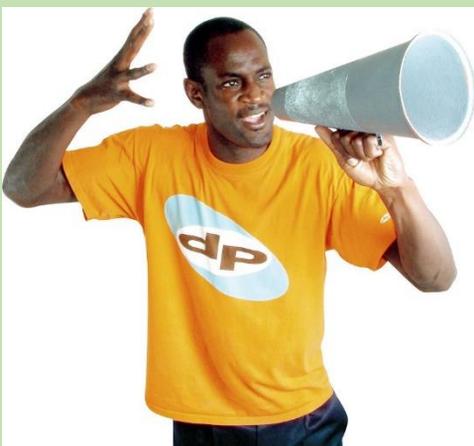
But 'Asian' people can be Pakistani, Chinese, Bangladeshi, Japanese...and many more



We also need to look at smaller groups to see if their experiences are the same or not



We need more research about different ethnic minorities



We need researchers to tell us more detail about people's ethnicity



The third part of our report is about **what people told us** about problems with health care



We talked to people with a learning disability from ethnic minority backgrounds and their carers



We asked people about **discrimination**



This is being **treated unfairly** because of who you are



Racism is being treated unfairly or badly because of your ethnicity or skin colour



Lots of people said they were **treated unfairly** because they have a **learning disability**



But some people find it **hard to tell** when this is racism



Some people **did experience** racism



Some people are **spoken to in a mean way** because of their ethnicity



Or **asked to pay** for treatments that should be free



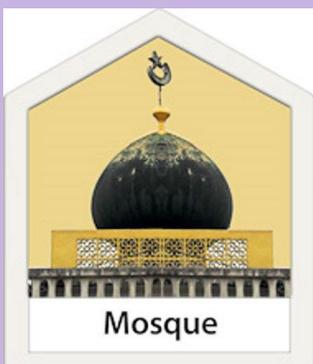
Some carers said that because they were **Asian**, healthcare staff **guess** they have a big family who help them



Even though this is **not true** and they do not have family to help them



Some people said that **religious and cultural activities** are important to them



This can include things like going to the Mosque or praying



But people said that there are **not enough staff** that understand your culture and religion



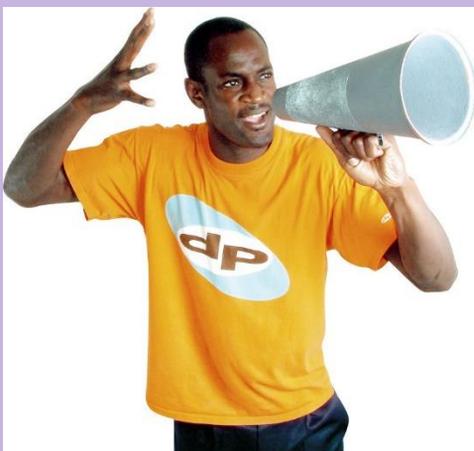
This can stop you from being a part of your community



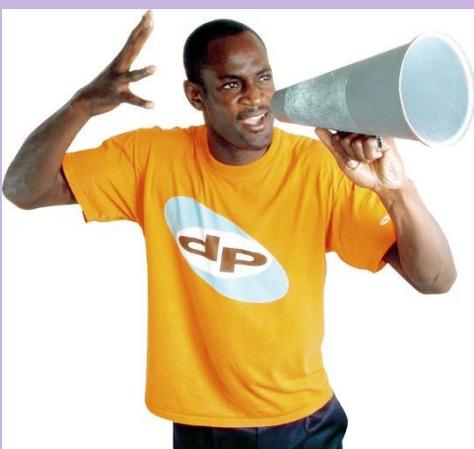
Carers said sometimes others in the Asian community **don't understand** what a learning disability is



This makes carers feel **lonely**



We need people of every ethnicity to be treated fairly



We need healthcare staff to understand everyone's situation is different



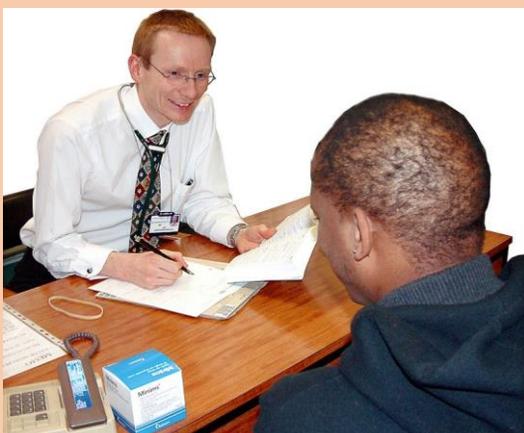
The fourth part of our report is about **how doctors write about your ethnicity**



Doctors write **information** about you in their **records**



This information helps them know what **support** you need and how to help you



One thing they write about is your **ethnicity**



It is important this information is **right**



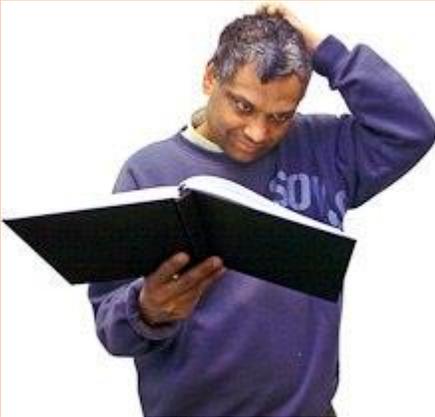
Your ethnicity is important because it affects your health



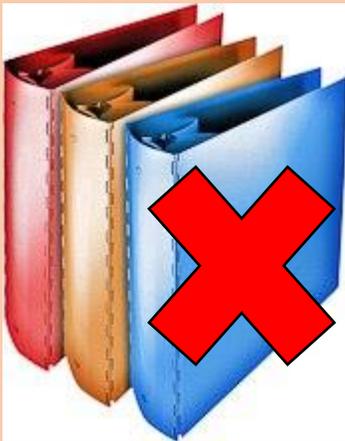
It affects your risk of getting certain illnesses



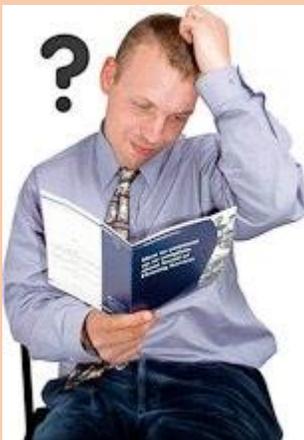
We looked at how doctors write about ethnicity



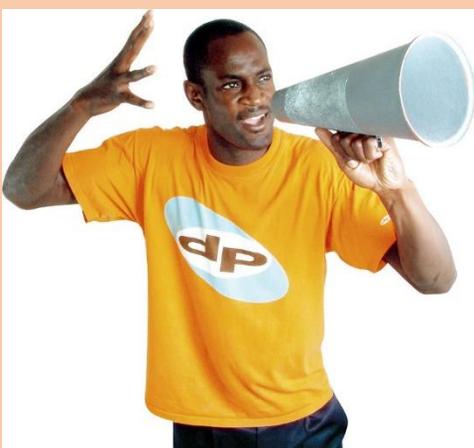
We found there were **lots of different ways** doctors write about ethnicity



This means the information they have about ethnicity might not be **right**



Or it might not be easy to **understand**



We need all doctors to have the same instructions about how to write about your ethnicity



The fifth part of our report looks at what **LeDeR** found about people who died



LeDeR look at the lives and deaths of people with a learning disability and autistic people



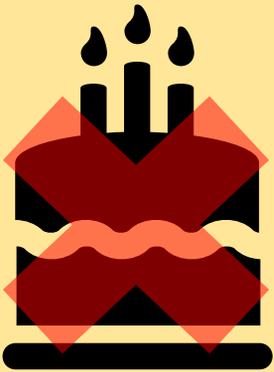
When someone dies with a learning disability, they can have their death **reported to LeDeR**



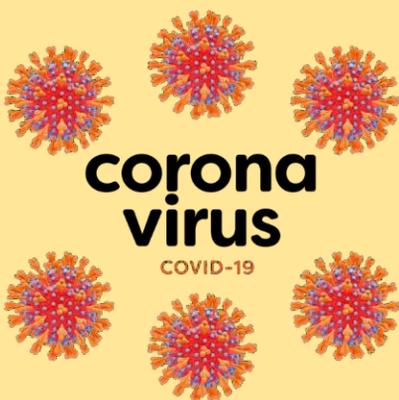
People then do a **review** of the person who died - which means looking at what happened to them



We looked at people who died who were from an **ethnic minority background** with a learning disability



People from an ethnic minority **died younger** than white people



All ethnic minority people were more likely to die of **COVID-19** than white people



For **every 10 people** who had their death reported to LeDeR, **9 were white**



Not enough people from an ethnic minority background are reported to LeDeR when they die



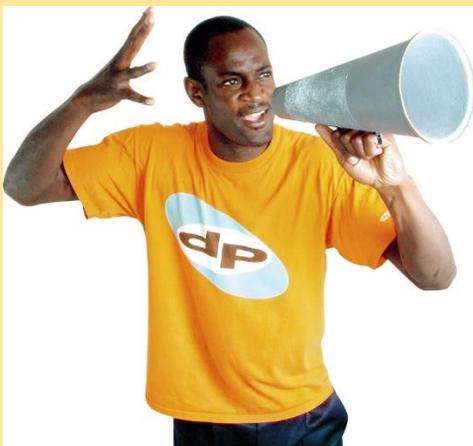
This means we **do not have enough information** about people from ethnic minorities



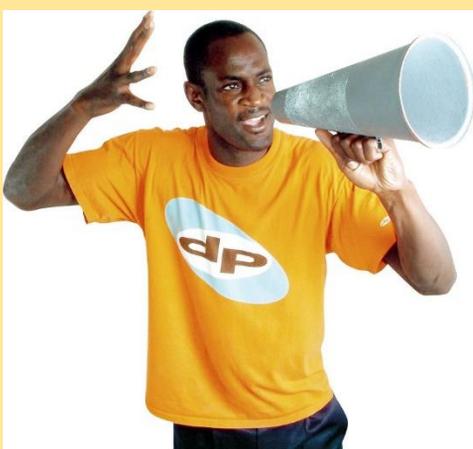
We asked people with a learning disability and their carers about LeDeR



People told us they **do not know what LeDeR is**

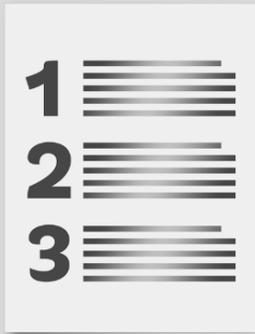


We need more people to know about LeDeR



We need more people from ethnic minority backgrounds to be reported to LeDeR when they die

We found...



There are not enough **policies**



There is not enough **research**



People with a learning disability from ethnic minority backgrounds **have lots of problems with their care**



Doctors do not always have the **right information** about your ethnicity



People with a learning disability from ethnic minority backgrounds **may die at a younger age** than people who are white

This is what we want to happen...



We want **more policies** so we can make services better



We want **more research** so we know more about people with a learning disability from different ethnic groups



We want healthcare services to understand **everyone's situation is different** and **treat everyone fairly**



We want **better instructions for doctors** so the information they have about ethnicity is right



We want **more people to know about LeDeR** so we can learn more about people who die from an ethnic minority background

This is an easy read version of the full *'Ethnic minorities with a learning disability and access to healthcare'* report.

You can read the [full report here](#)

This easy read report was prepared by Christina Roberts in collaboration with the Working Group.

This work was funded by the NHS Race and Health Observatory.

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