



Preventing poorer experiences and outcomes for people with a learning disability from Black, Asian and minoritised ethnic backgrounds.

Jabeer Butt, OBE
Chief Executive

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Overview

- Explore the evidence poorer experiences and outcomes for people with learning disability from Black, Asian and minoritised backgrounds;
- Reflect on the drivers of these comparatively poorer experiences and outcomes, including the role of racism;
- Highlight some approaches that will help address the poorer experiences and should lead to better outcomes

Some of the words and ideas in
this presentation

“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



Everybody looks different.

Lots of people have
different skins colour.



People experience
things differently
because of their
different skin colours.



Some people are
treated badly because
of their skin colour.

This is racism.

What is racism

Racism Explained

An easy-read guide explaining
race and racism

By

Ambitious about Autism

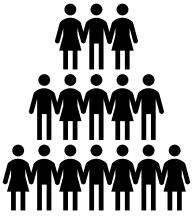
We Deserve Better report

1. What do we know about the current cause of health inequalities in relation to access, experience and outcomes?
2. What are the current approaches through policies to addressing health inequalities?
3. Can differences in outcomes be quantified through data available?
4. Do the findings from answering the above questions fit with lived experience?

Background & Methodology

- This project was a collaboration between the University of Central Lancashire, Manchester Metropolitan University, the Race Equality Foundation and Learning Disability England.
- We used an experience-based co-design approach. This means the research was guided by a Working Group of 'experts by experience' who are people with a learning disability from ethnic minority backgrounds and/or their carers.
- The Working Group were involved at every stage of the research process, from helping with ethics applications, to informing the foci of the work, to disseminating findings.

Background



Over 1.3 million people in England have a learning disability (Mencap, 2019). However, there is a paucity of data around the proportion of this population who are also from an ethnic minority.



People with learning disabilities from ethnic minorities are at risk of 'double discrimination' as members of two minoritised groups.



Evidence from Learning from lives and deaths – people with a learning disability and autistic people (LeDeR) suggests people from ethnic minorities have some of the poorest outcomes.

Prevalence



In this presentation prevalence means the total number of people in a community who have a learning disability at a specific period of time.



In 2007 a research study found that there are at least 60,000 people with learning disabilities from 'black and minority ethnic communities' in the UK.



But the not so good news is that in 2005 research said that less than 25% of 'black and minority ethnic people' with learning disabilities are known to services.

Prevalence

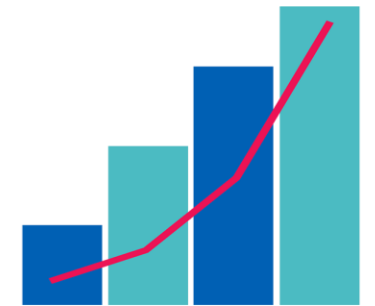
In 2001 a research study looked the number of people aged between 5 and 32 with 'learning difficulties' from a South Asian background.

The researchers found that number of people with a learning disability is up to 3 times higher than in other communities.

South Asian children under 5 years old often do not get a diagnosis of a learning disability. This means that the prevalence rates are reported as lower.

19% of South Asian families caring for family members with learning difficulties had more than one member with a learning difficulty.

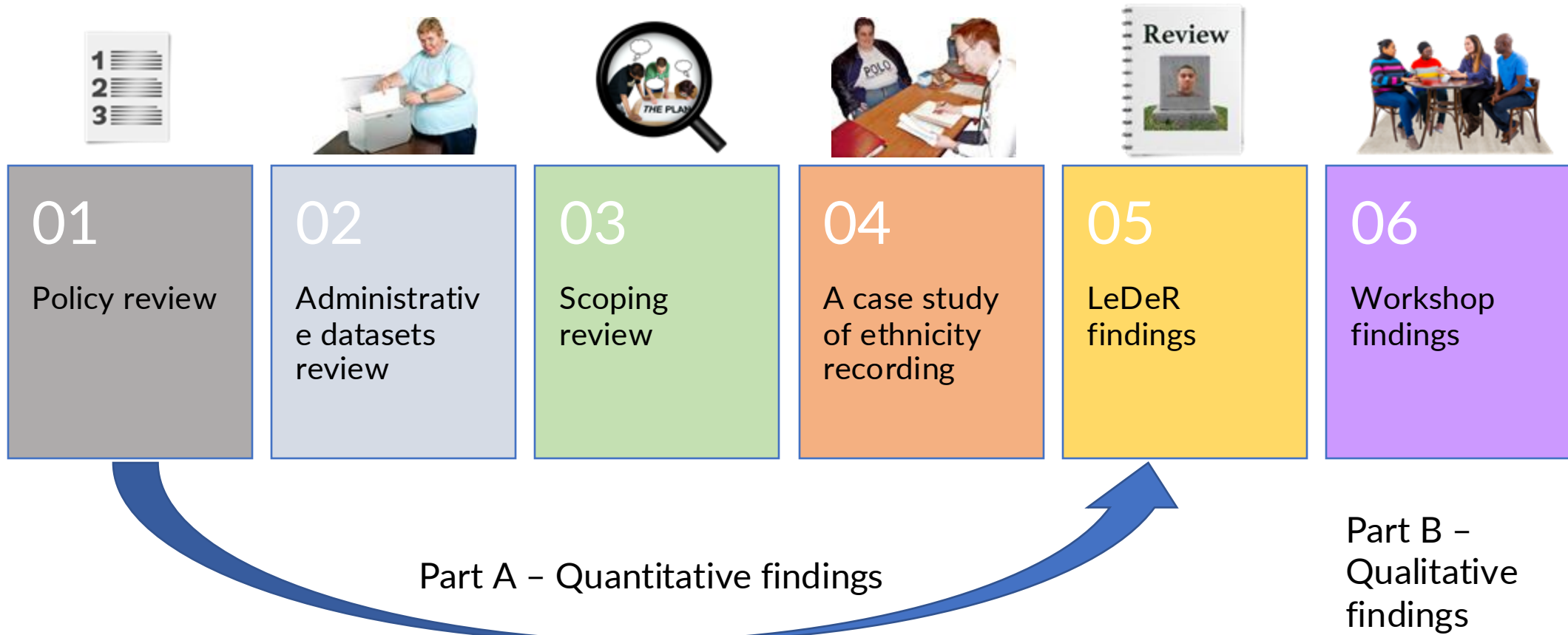
We do not know much about the numbers of people with a learning disability from other minority ethnic groups. However, there is some evidence to suggest that could be quite a higher prevalence within the African Caribbean community too.



Health Inequalities

- People from ethnic minority backgrounds had a lower median age at death, regardless of the severity of their learning disability
- Black, Black British, Caribbean or African ethnicity has been associated with the highest risk of death at a younger age compared to the white population
- People from ethnic minority backgrounds with a learning disability were disproportionately affected by COVID-19

Sections of the Report



Section 1 Summary – Policy Review

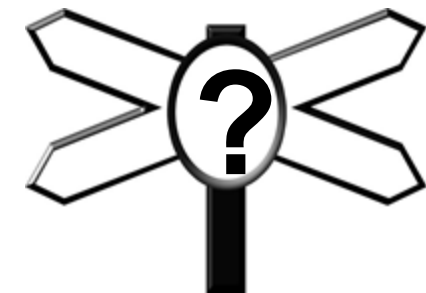
Policies are written by the government to tell services (doctors, hospitals) what they should do to support people.

We looked at **36 policies** to see what they said about people with a learning disability from ethnic minorities.



We found that policies **rarely** included information about people with a learning disability from ethnic minorities.

This means services do not have **clear instructions** from the government about how to help.



Section 1 – Policy Review

- We reviewed 36 national policy documents for England from 2001 onwards, including:
 - NHS England and other national policies relevant to people with a learning disability
 - Department of Health and Social Care responses to reports
 - Relevant White Papers
- Policies rarely mention inequalities in the lives of people with a learning disability from ethnic minorities.
- Recently, government responses to the LeDeR reports have recognized these inequalities.
- Specific policy directions relating to people with a learning disability from ethnic minorities are rare.

Section 2 Summary – Administrative Datasets Review

Administrative datasets are big files of information about people collected by organisations (like the NHS and local councils).

We looked at **27** datasets to see what information they have about learning disability and ethnicity.



We found that datasets have **different ways** of describing ethnicity and learning disability which can make them **hard to understand**.

At the moment, datasets are not being used to keep an eye on the health and experiences of people with a learning disability from ethnic minorities.



Section 2 – Administrative Dataset Review

- We looked at 27 routine administrative datasets for England to determine the feasibility of analysing data relating to people with a learning disability from ethnic minorities.
- We found that because different datasets have different purposes relying on different information systems, criteria for learning disability and ethnicity vary.
- Five of the 27 datasets contained publicly available information that compared some aspect of the experience of people with a learning disability across ethnic groups.
- The potential for administrative datasets to provide ongoing monitoring of the health, experiences and service responses to people with a learning disability across ethnic groups is under-utilized at the moment.

Section 3 Summary – Scoping Review

Scientists write articles to tell people about the work they do. This is called **research**.

We looked at **what we already know** from research about people with a learning disability from ethnic minority backgrounds.

We found that there is **not enough research** about people with a learning disability from ethnic minorities.



Lots of the research we did find looked at '**South Asian**' people. Not enough research looked at other ethnic minorities.

Big groups like 'Asian' are often used in research. It can be useful to use big groups.

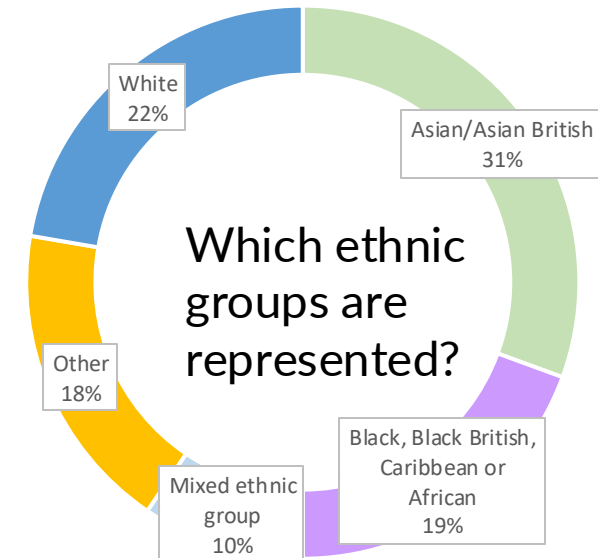
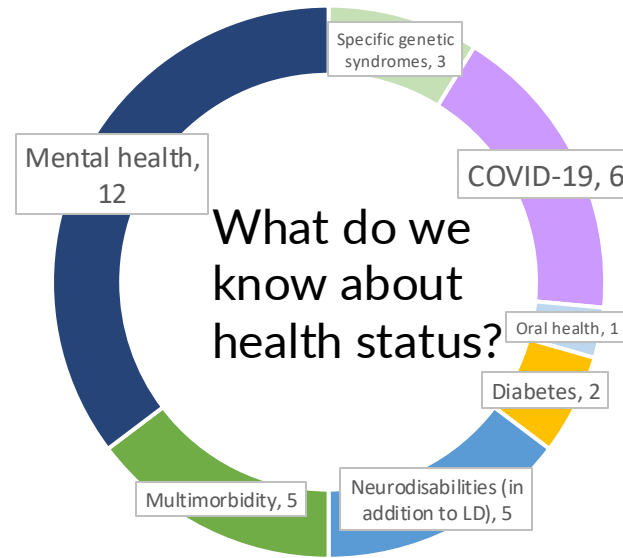
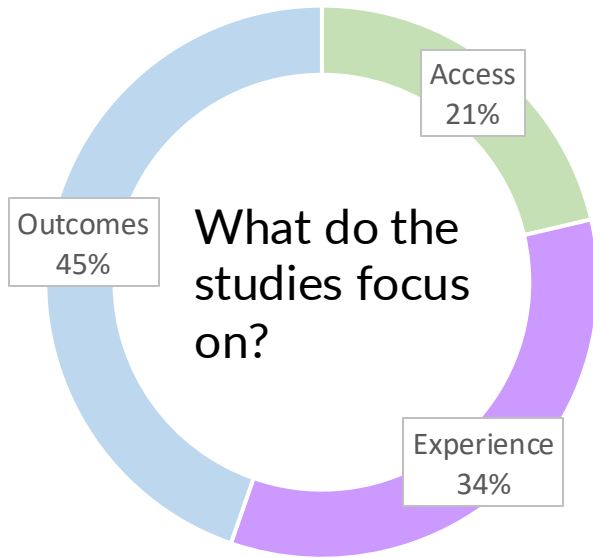
But it is important that researchers try to look at **smaller groups** to see if their experiences are the same.



Section 3 – Scoping Review

- **Literature search:**
 - We conducted an electronic database search – focusing on access, experience and outcomes of healthcare
 - We screened the papers, and 94 papers were included in the final review.
 - Thirty-six were mixed-methods and qualitative papers, the remaining papers were quantitative.
- **Themes:**
 - Preliminary findings from the final sample of papers were discussed with the Working Group.
 - The themes to explore in the review were developed through an iterative process between the academic team and working group.

What did we find?



Findings – Themes

Discrimination

- Only **two studies explicitly focused on discrimination** (Ali et al., 2013; Azmi, Hatton, Emerson & Caine, 1997).
- Several studies discussed lack of culturally appropriate services and language barriers.
- Discussion of barriers through the lens of discrimination or racism was rare.

Community and family networks

- ‘South Asian’ groups had **more family members in their social network** who acted as support (Bhardwaj, 2018; O’Hara, 2003)
- **High levels of stress and psychological symptoms in carers** (e.g. Akbar et al., 2020; Masefield et al., 2022)

LeDeR

- LeDeR reports suggest that people from ethnic minority groups **may die at a younger age**.
- Males from an ‘Asian/Asian British’ background with profound and multiple learning disability had a median age at death at around **30**.
- This is the **lowest** median age at death of all ethnic groups (Heslop et al., 2020).

Findings – Themes

COVID-19

- Being from an ethnic minority and having a learning disability were both factors associated with an **increased risk of adverse COVID-19 health outcomes** (e.g. LeDeR 2020).
- **Ethnicity and having a learning disability were identified as independent risk factors** (e.g. Carey et al., 2021; Cummins et al., 2021).

Transitional care

- Greater levels of unmet needs in relation to culturally appropriate services in those from 'South Asian' backgrounds compared to those of 'Caucasian' ethnicity (Bhaumik et al., 2011).

The learning disability register

- One paper (Chaplin et al., 1996) found **'Asian' adults are underrepresented on the register**.
- Nine papers used the learning disability register as part of their recruitment or analysis.

Section 4 Summary – Ethnicity Recording

Doctors write information about you in their **records**. This includes information about your **ethnicity**.

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

Your ethnicity information is **important** because different ethnic groups are at risk of different problems.



We looked at **what doctors write** about ethnicity in records.

We found there **are lots of different** ways doctors write about ethnicity in their records.

This means the information they have is not always **right** and can be hard to understand.



Section 4 – A Case Study of Ethnicity Recording

- Capturing accurate ethnicity data is important to uncover potential patterns of disadvantage for different ethnic groups, bias and racism.
- Ethnicity is a self-identified construct which may be challenging for people with a learning disability who may rely on others for definition and explanation.
- We conducted a case study to explore the quality of ethnicity codes of patients on the learning disability register held in GP clinical records within the Lancashire and South Cumbria ICB.

Findings

Completeness:

- 92.6% of records contained an ethnicity code.



Validity:

- 73.4% of these codes were valid according to the NHS Data Dictionary
- 72.7% were valid according to census categories



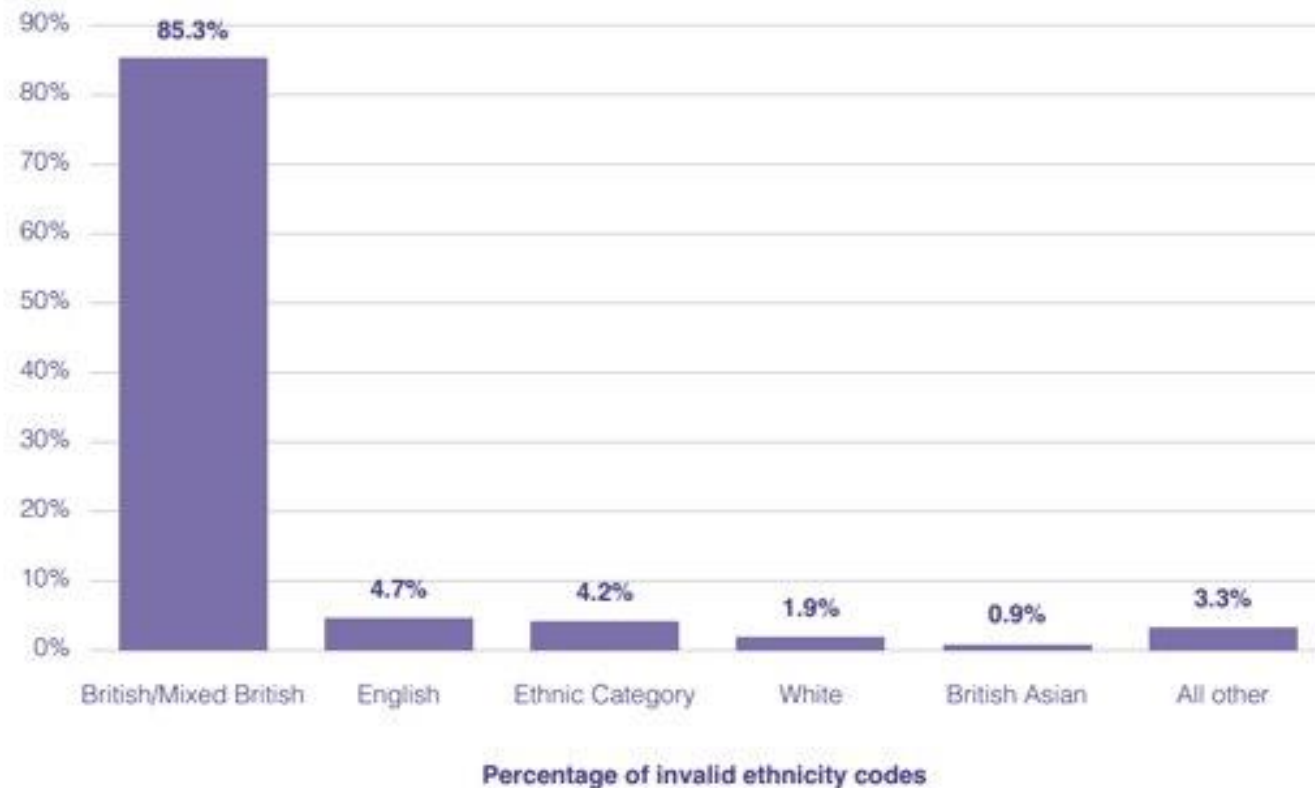
Prevalence of learning disability:

- Overall, 0.57% of patients in the Lancashire and South Cumbria ICB were on the learning disability register



Findings

26.6% of ethnicity recordings could not be classified according to the NHS Data Dictionary



Conclusions ethnicity recording

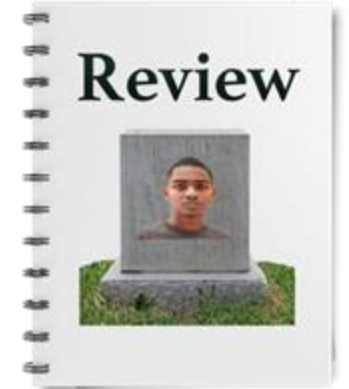
- The analysis highlighted significant issues with ethnicity coding of patients on the learning disability register within Lancashire and South Cumbria.
- Although most people have an ethnicity recorded, just over 25% of the ethnicity codes are not valid according to either the NHS Data Dictionary or the 2011 census.
- There is no mandated procedure for collecting ethnicity in the NHS.
- Organisations use different coding systems, and guidance has not been updated since 2001.

Section 5 Summary – LeDeR Findings

LeDeR looks at the **lives and deaths** of people with a learning disability and autistic people in England.

When someone dies, they can have their death **reported** to LeDeR. A reviewer then looks at what happened to them and writes a **review**.

We looked at people who died between **2018 and 2021** from an ethnic minority background with a learning disability.



We found that people from ethnic minorities **died younger** than 'white' people.

For every 10 deaths reported to LeDeR, **9** are of people who are '**white**'.

Not enough people know about LeDeR and we **do not have enough information** about people from ethnic minorities who die.



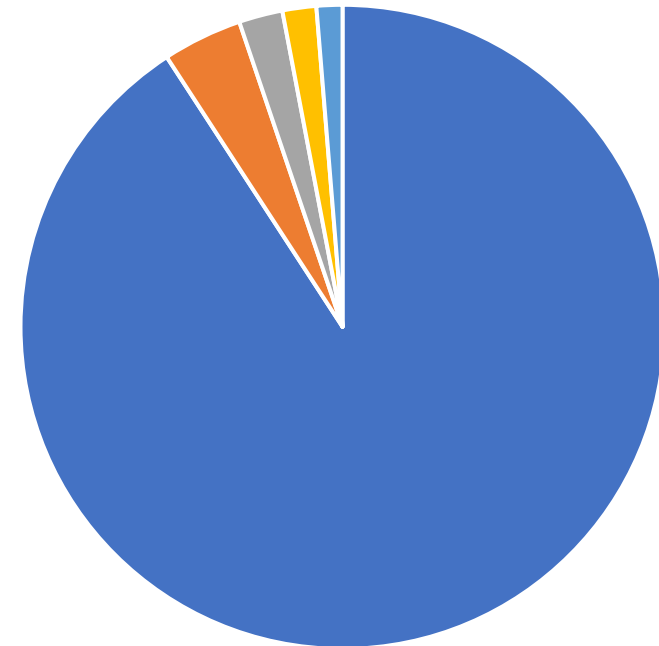
Section 5 – LeDeR Findings

- The LeDeR programme (Learning from lives and deaths – people with a learning disability and autistic people) reviews the deaths of people with a learning disability (and autistic people as of June 2021) over the age of 4.
- We used data from notifications to the programme and completed reviews of deaths from 2018-2021.

Notifications of Deaths of People from Ethnic Minorities

For every 10 deaths reported to LeDeR between 2018 and 2021, 9 were of people denoted as 'White'.

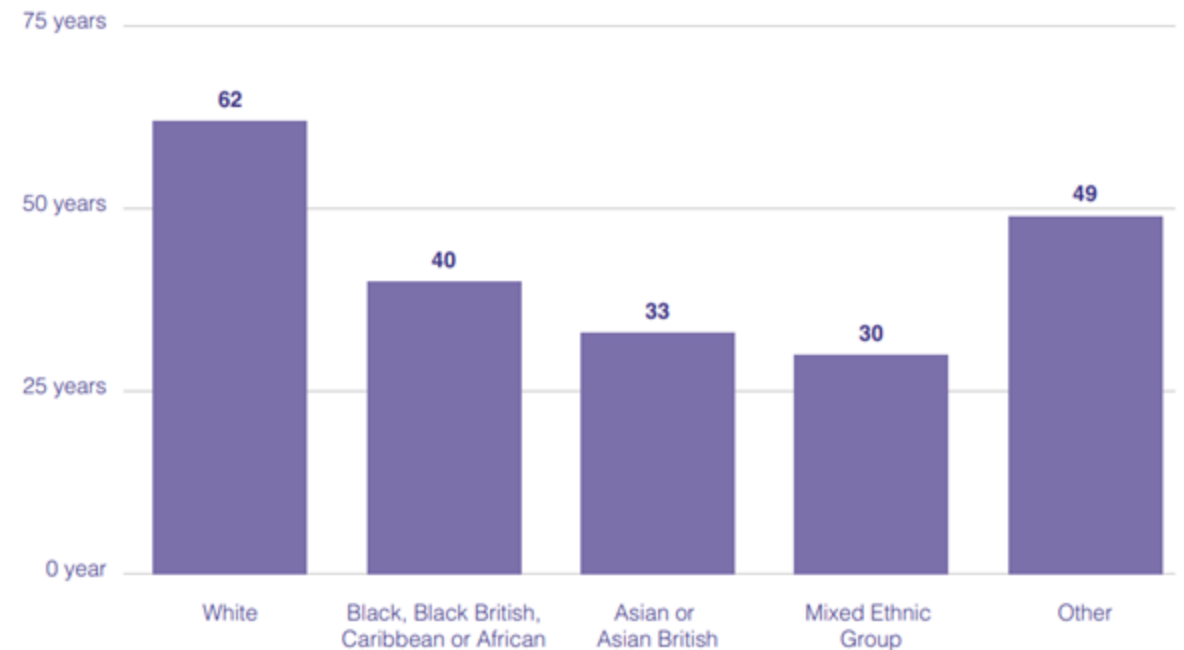
% of notifications



- White
- Mixed
- Black, Black British, Caribbean or African
- Asian or Asian British
- Other

Median Age at Death

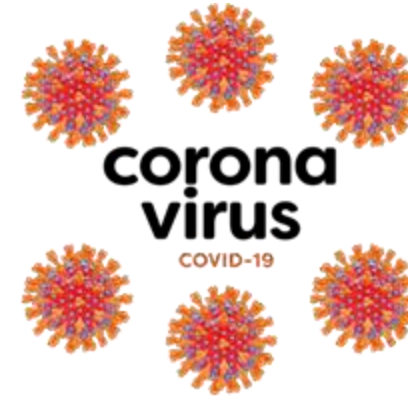
- The median age at death for people from ethnic minority groups was **34 years** (min=4; max=96), compared to **62 years** (min=4; max=104) for people denoted as 'white'.
- However, the number of people in the ethnic minority group is **considerably smaller** than those in the 'white' group so this must be interpreted with caution.



Leading Causes of Death by Ethnicity

Asian or Asian British – influenza and pneumonia
Black, Black British, Caribbean or African – cerebral palsy and other paralytic syndromes
Mixed – not reported
Other – cancer
White – cancer

2018–2019



2020–2021

Asian or Asian British – COVID-19
Black, Black British, Caribbean or African – COVID-19
Mixed – COVID-19
Other – COVID-19
White – COVID-19

What do we not know?

- How many people from ethnic minority have a learning disability?
- How many people from ethnic minority with a learning disability receive an annual health check?
- Why is there an under reporting of deaths to the LeDeR Programme?

Section 6 – Easy Read Summary

The last part of the report is about what people told us about their care.

We spoke to self-advocates, carers and support workers.



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

But people found it hard to understand if they had experienced **racism**. This is when you are treated unfairly or badly because of your ethnicity.



Section 6 – Easy Read Summary

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

Even though this is not true and they **do not have help from family**.



People told us there are **not enough staff from their culture** and this makes them miss out on being in their community.

Carers said sometimes people in their community **do not understand what learning disability is**. This makes them feel lonely.



Section 6 – Workshop Findings

Methods

- **Experience-based co-design (EBCD)** workshops were conducted between October and November 2022.
- **Participants:** 20 (13 self-advocates, 5 family carers and 2 support workers) participants from EM backgrounds were recruited through a range of public advertising methods and existing networks of project partners.
- **Workshops:** Three EBCD workshops (Lewisham, Leeds and online). People who could not attend the workshops provided their thoughts directly with the research team. Eight core themes were focus points for discussion which were generated through discussion with a working group and a scoping review.
- **Analysis:** The workshops were audio recorded, transcribed and thematically analysed.

Findings

Discrimination

- Some participants experienced discrimination but found it hard to tell whether this was ableism or racism.
- People reported instances of reasonable adjustments not being adhered to.
- Some participants provided personal experiences where they acknowledged that they may have been treated differently due to their ethnic background.
- Examples included being spoken to in a distasteful or derogatory way, being denied access to treatment that was deemed to be beneficial or being prompted to pay for services which were expected to be free.

Community and family networks

- Support from these networks were important for the general health and wellbeing of self-advocates.
- Support from self-advocacy groups was particularly important for people who lacked frequent family support, however sometimes culturally appropriate services were unavailable.
- Carers also expressed that they lacked support from their wider family and within their communities, possibility due to the stigma of learning disability, which resulted in feelings of isolation.
- Their experiences did not align with the findings from the scoping review and felt like healthcare professionals also held the stereotype that 'South Asian' families have big support networks.

LeDeR

- There was a lack of knowledge of the programme.
- Participants reported that targeted information about LeDeR to raise awareness of the value of the programme would be beneficial.

Findings

COVID-19

- Difficulties with access were exacerbated during the pandemic.
- Self-advocates spoke of the loneliness and uncertainty caused by the abrupt and prolonged reduced access to support networks.

Transitional Care

- Carers spoke of a lack of support and information during periods of transition, which caused carers of younger children fearing the transition to adult services, particularly from a health care perspective.
- A noticeable barrier was a lack of communication between healthcare services.

The learning disability register

- Despite people receiving annual health checks, there was a lack of awareness of the learning disability register, among both self-advocates and carers.
- Self-advocates identified fear as a potential barrier to wanting to be on the learning disability register.

Findings

Digital Access

- Self-advocates expressed that whilst they have mainly adjusted to using digital technology for health and care purposes, they still require support.
- Participants reported a shortage of accessible healthcare information online.
- Participants stressed that being able to engage with health and care services digitally should be a personal choice, that is inclusive of their needs.

Implications

- The intersection of disability and ethnicity results in **compounded discrimination**.
- This discrimination exacerbates inequalities in access and experiences of healthcare for people with a learning disability from ethnic minority backgrounds.
- However, recognising and understanding the source of discrimination can be difficult for people.
- These disparities can be reduced by clinicians having effective communication and an enhanced understanding of learning disability.
- Understanding an individual's needs from the first point of contact is important for the allocation of resources.

Contact Details

Jabeer Butt, Race Equality Foundation

jabeer@racefound.org.uk

Prof Umesh Chauhan, University of Central Lancashire

UChauhan@uclan.ac.uk

