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BARRIES TO HEALTHCARE FOR PEOPLE WITH A LEARNING DISABILITY FROM ETHNIC MINORITY BACKGROUNDS

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Overview

Why does it matter?

What barriers do people with a learning disability from an ethnic minority group face in healthcare?

How can we improve healthcare?

Building a better future

Padlet Questions

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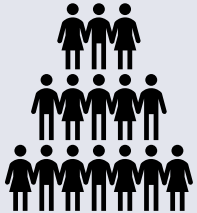
https://uclan.padlet.org/uchauhan/my-portfolio-tt5i9gkkyfm64wdn

Why does this matter?

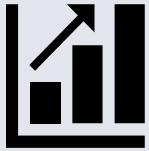
- Healthcare is a basic right but people with learning a disability from ethnic minorities face major barriers in the UK.
- Barriers = poorer access, experience and outcomes.

Background



Over 1.3 million people in England have an Intellectual 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 intellectual 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.

Background

- Capturing accurate ethnicity data is important to uncover potential patterns of disadvantage for different ethnic groups, bias and racism.

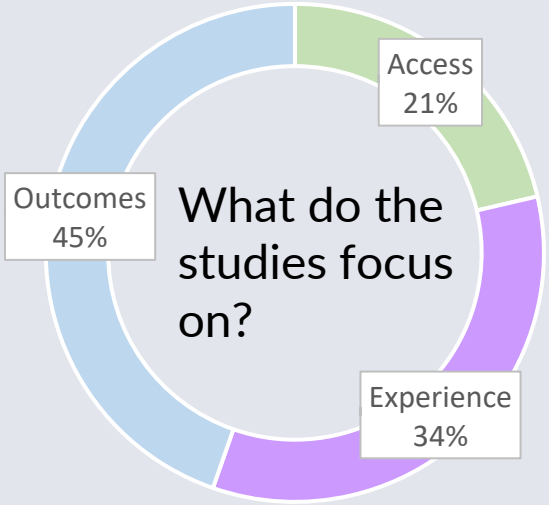
- Ethnicity is a self-identified construct which may be challenging for people with a learning disability who may rely on others for definition and explanation.

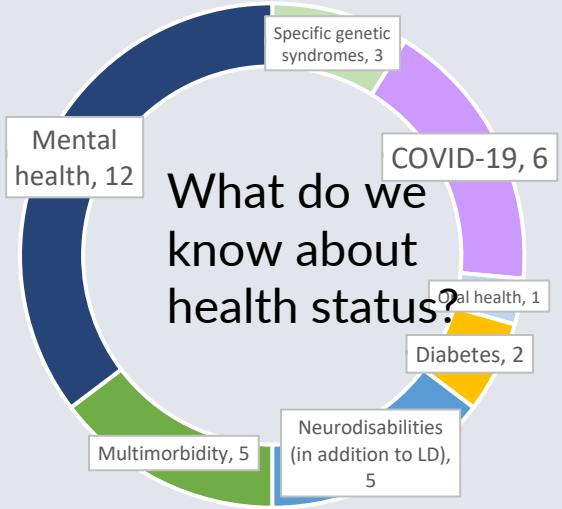
- There is no mandated procedure for collecting ethnicity in the NHS.

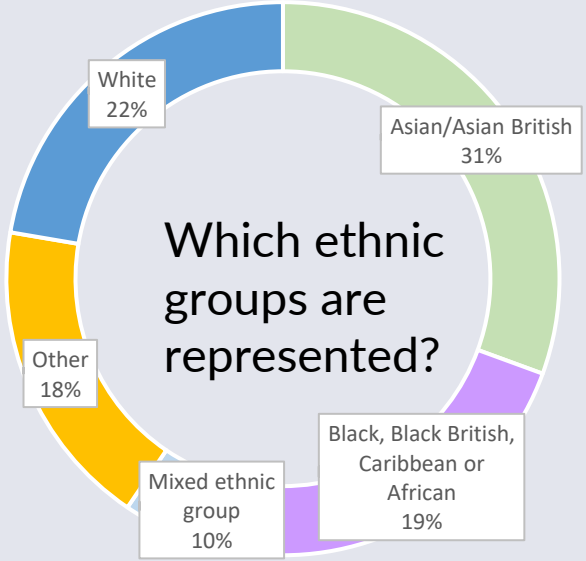
Background & Methodology

- 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.

Literature findings







Findings from literature

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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

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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.

Health Inequalities-LeDeR data findings

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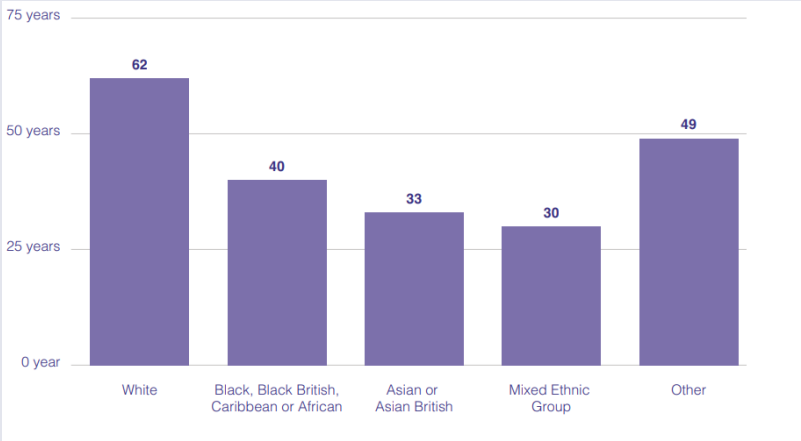
- People from ethnic minority backgrounds had a lower median age at death, regardless of the severity of their intellectual disability
- Black, Black British, Caribbean or African ethnicity has been associated with the highest risk of death at a younger age compared to the white population
- People from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

LeDeR Data -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.



A Case Study of Ethnicity Recording

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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 intellectual disability register

Culturally adaptive healthcare for people with a learning disability from an ethnic minority background: A qualitative synthesis

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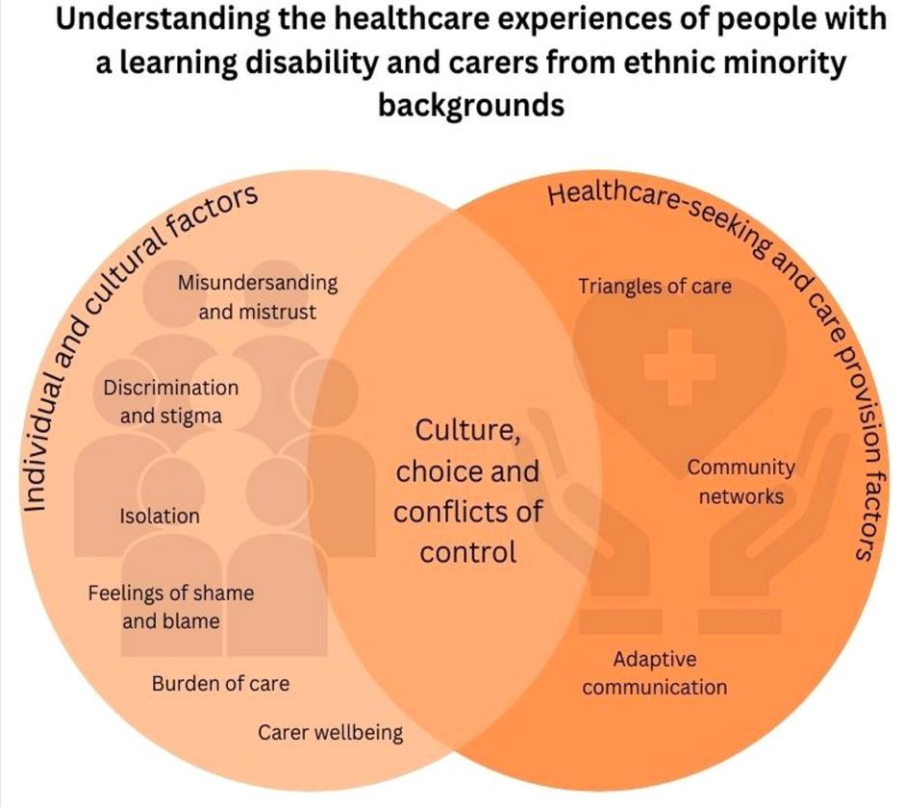
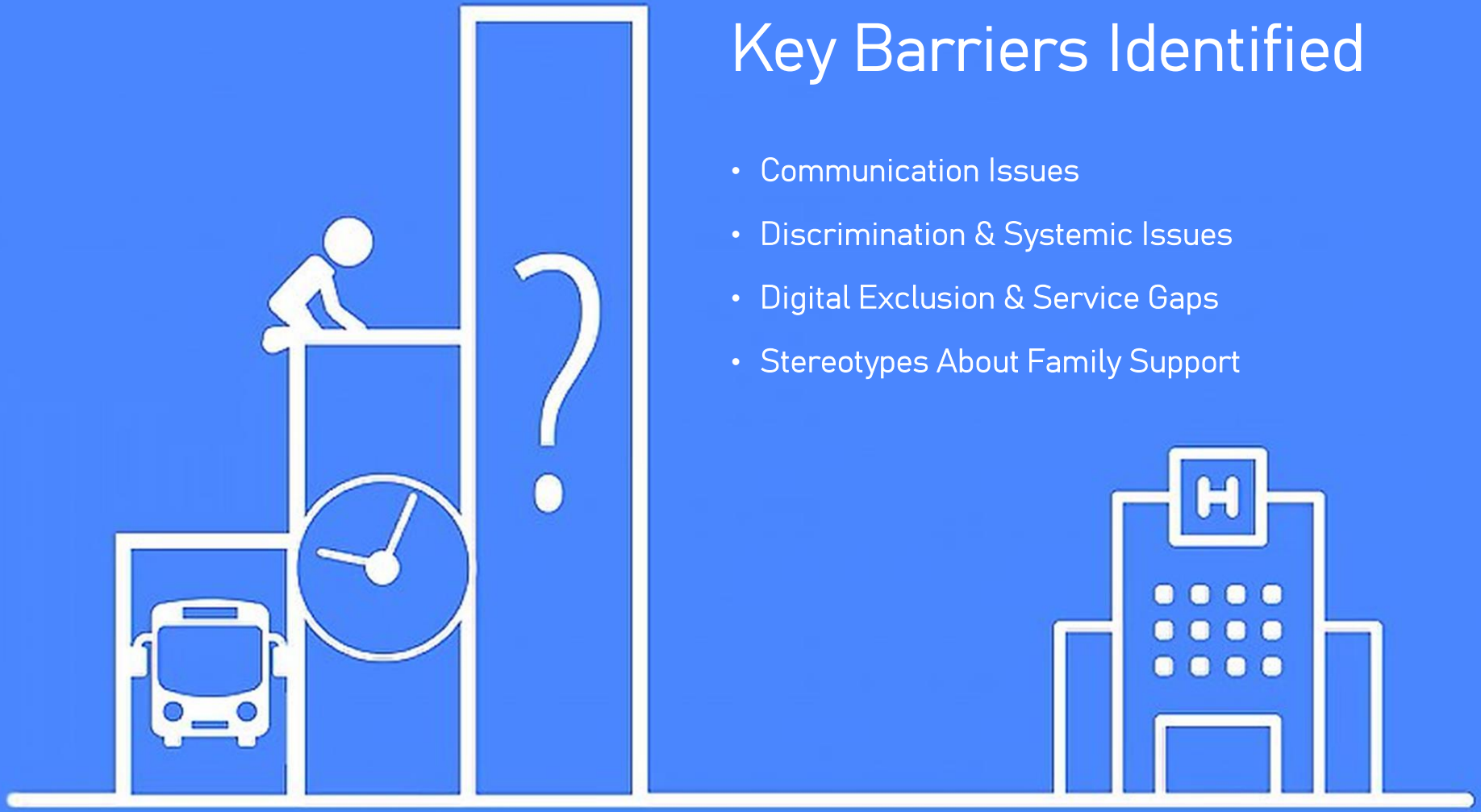


Brit J Learn Disabil, Volume: 53, Issue: 1, Pages: 32-42, First published: 12 August 2024, DOI: (10.1111/bld.12614)

Key Barriers Identified

- Communication Issues
- Discrimination & Systemic Issues
- Digital Exclusion & Service Gaps
- Stereotypes About Family Support



Communication

Doctors and healthcare staff don't always listen or provide interpreters and culturally appropriate resources.

This leaves patients feeling excluded and misunderstood.

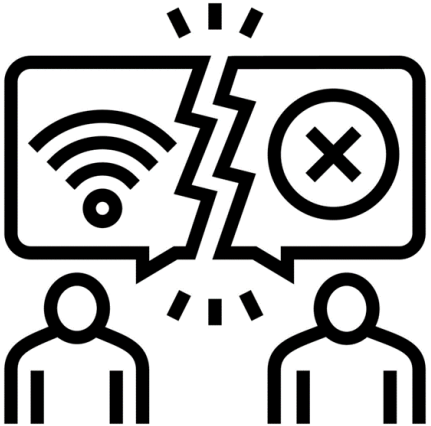
Discrimination & Systemic Issues

Many people experience discrimination both from healthcare services and within their own communities.

Lack of cultural competence among healthcare professionals makes access even harder.

Digital Exclusion & Service Gaps

Many healthcare services rely on digital access, which some people struggle with.



There's also a disconnect between different healthcare services, making care uncoordinated.

Stereotypes About Family Support

People assume ethnic minority families always provide strong support.

In reality, many feel isolated, especially during the COVID-19 pandemic.

Implications

- The intersection of disability and ethnicity results in **compounded discrimination**.
- This discrimination exacerbates inequalities in access and experiences of healthcare for people with an intellectual 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 intellectual disability.
- Understanding an individual's needs from the first point of contact is important for the allocation of resources.


How can we improve healthcare?

The Access Model

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- Assessment
- Communication
- Cultural negotiation and compromise
- Establishing respect and rapport
- Sensitivity
- Safety

Better Communication & Awareness

- Raising awareness about resources like the Learning Disability Register.

- Training healthcare staff to provide person-centred care

Investing in Cultural Support

Creating roles like ethnic minority liaison officers who know and understand our cultural needs.

Increasing diverse learning disability nurses

Improving Healthcare Transitions

CHILD

Ensuring smoother transitions between child and adult healthcare services.

Making the system more coordinated.

ADULT

Co-Designing Solutions

Working with self-advocates, carers, and community groups to shape policies that work

Summary

Breaking these barriers requires

- Systemic change
- Collaboration.
- Cultural awareness

By making small but meaningful changes, we can ensure healthcare is truly inclusive for everyone.

Future Research

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TRANSFORM Prostate Cancer Screening Trial

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https://prostatecanceruk.org/research/transform-trial

TRANSFORM - Population

- Men aged 50 to 75 years
- Men aged 45 to 50 with Black ethnicity and people with a learning disability
- No previous prostate cancer
- No recent PSA test, prostate MRI, prostate biomarker test or prostate biopsy
- Stage 1: identify men through primary care
- 10% of invited population to have Black ethnicity

PROSTATE CANCER UK
TRANSFORM

Join our Family Carer Steering Group

Are you the family carer of a child with a learning disability?
We need your help!

<u>The project</u>: Increasing the uptake and quality of annual health checks in children and young people aged 14-17 years with a learning disability

<u>What does it involve?</u>

- **Joining 3 online meetings per year (a total of 9 times over 3 years)**
- **Working with researchers and other family carers to shape the research and results**
- **Giving researchers advice about the project**
- **Helping to design materials to share the research results with other family carers**

You'll be paid £75 for each half-day online meeting

To express interest, or ask for more information, please contact Samantha Flynn: S.Flynn.1@warwick.ac.uk

References

- We deserve better: Ethnic minorities with a learning disability and access to healthcare - Race Equality Foundation (2023)Umpleby, K., Roberts, C., Cooper-Moss, N., Chesterton, L., Ditzel, N., Garner, C., Clark, S., Butt, J., Hatton, C., Chauhan, U. https://raceequalityfoundation.org.uk/press-release/we-deserve-better-ethnic-minorities-with-a-learning-disability-and-access-to-healthcare/
- Culturally adaptive healthcare for people with a learning disability from an ethnic minority background: A qualitative synthesis (2024) Roberts, C., Ditzel, N., Cooper-Moss, N., Umbleby, K., Chauhan C. https://doi.org/10.1111/bld.12614
- Barriers to Healthcare for People With a Learning Disability From Ethnic Minorities: Perspectives of Self-Advocates and Carers (2024) Cooper-Moss, N., Umpleby, K., Roberts, C., Garner, C., Hazel Edwards, A., Ditzel, N., Butt, J., Clark, S., Hatton, C., Chauhan, U. https://doi.org/10.1111/bld.12636

Thank you!

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