



University of  
Central Lancashire  
UCLan



NHS  
RACE & HEALTH  
OBSERVATORY

# PART A

## We deserve better: Ethnic minorities with a learning disability and access to healthcare – a review of policy and data

July 2023

# Contents

Acknowledgements	3
Abbreviations	7
Approach to terminology	8
Introduction	9
<b>Section 1:</b> Policy review	<b>14</b>
<b>Section 2:</b> Administrative datasets review	<b>16</b>
<b>Section 3:</b> Review of factors that impact access, experience and outcomes	<b>20</b>
<b>Section 4:</b> Case study of ethnicity recording	<b>32</b>
<b>Section 5:</b> LeDeR Data Analysis	<b>43</b>
Summary	58
References	60

# Acknowledgements

This work was commissioned by the NHS Race and Health Observatory. The University of Central Lancashire worked alongside partners at Manchester Metropolitan University, Learning Disability England, and the Race Equality Foundation. A working group, including people with lived experience, supported the delivery of the project.

- **Prof Umesh Chauhan**  
Professor of Primary Care at *the University of Central Lancashire*.
- **Katie Umpleby**  
Research Assistant at *the University of Central Lancashire*.
- **Christina Roberts**  
Research Assistant at *the University of Central Lancashire*.
- **Prof Chris Hatton**  
Professor of Social Care at *Manchester Metropolitan University*.
- **Dr Lorna Chesterton**  
Social Scientist and Researcher at *Manchester Metropolitan University*.
- **Dr Nicola Cooper-Moss**  
GP in Lancashire and NIHR In-Practice Fellow at *the University of Manchester*.
- **Jabeer Butt OBE**  
Chief Executive of *the Race Equality Foundation*.
- **Sam Clark**  
Chief Executive Officer at *Learning Disability England*.
- **Christie Garner**  
Policy and Practice Officer at *the Race Equality Foundation*.
- **Nicola Ditzel**  
Undergraduate student and intern at *the University of Central Lancashire*.

We would also like to thank other people who have contributed to this work:

- Adam White
- Alice Pritchard
- Morris Gordon
- Nadeem Gire
- Samukeliso Fundira
- Serena Liang
- Vasiliki Sinopoulou

## The working group

---

A working group was formed consisting of people with lived experience who worked closely with the academic team. Members of this group had previous experience of working with the Race Equality Foundation (REF), Learning Disability England (LDE) and Pathways Associates. Both REF and LDE provided support as necessary, including the provision of training and information in an accessible format. The working group consisted of ten people with lived experience as an ethnic minority self-advocate, family member or supporter. The group was co-chaired by Sam Clark (LDE, Chief Executive) and Aisha Edwards (Lewisham Parliament Representative).

The group met monthly to inform different aspects of the project, including:

- Scoping the review criteria and search terms, sharing their priorities for investigation and reviewing the first phase findings
- Contributing to defining the focus of the policy review
- Designing workshop plans, including making the sessions inclusive and welcoming for all people
- Reviewing and improving the public workshop information and participant consent forms to improve accessibility
- Supporting the promotion of the workshops
- Providing insight on themes emerging from the workshops

The working group also discussed the challenges raised by the ethics committee, giving the research team feedback from their lived experience on consent and on the way this work describes the inequalities and early deaths of ethnic minority people with a learning disability.

The following profiles have been provided by members of the working group who wished to be cited in this report:

### **Siraaj Nadat**

*“My name is Siraaj Nadat, Senior Quality of Life Facilitator at rights-based organisation Changing Our Lives. Through our work around social justice I have been heavily involved in tackling the health inequalities faced by people with a learning disability and autistic people. Using this knowledge, I was able to valuably contribute to the working group. At Changing Our Lives, we focus our work in and alongside minority ethnic communities, and through this and my own lived experience of being a disabled man from a minority ethnic community I am not only passionate to talk about the health inequalities that these communities face but to see change happen.”*

### **Mary Akinbiyi**

*“My name is Mary a retired retail manager. I am mother/ carer to my handsome son. My son suffers from brain injury, epileptic seizures, speech impairment and a learning disability. I generally have passion for people with a learning disability. I am an advocate because I know they need help to amplify their voices and support to live the life, they are entitled to.”*

### **Aisha Edwards**

*“I am Aisha Edwards and I work as a People Parliament Representative for Lewisham Speaking Up and I enjoy it.”*

### **Kizzy Felstead**

*“I am an autistic adult and mother to two autistic children. I have a background as a social worker and then teacher and have also taught English as a second Language to a variety of ethnic minority groups and have also taught children from Gypsy, Roma, Traveller communities. Whilst studying for an MSc, I also work as a trainer, delivering a variety of topics around autism and learning disability to people working in social care, Justice and Health systems. I am passionate about equity and making a difference to the lives of seldom heard from communities which is why I am working with this project.”*

**Sayed Ahmed**

*"I am a dedicated and passionate individual and a parent/carer and Health Professional who is very committed to reducing Health Inequalities and Inequities by working in partnership with others to work towards positive solutions and Equality for All."*

**Lee Scott**

*Lee is a representative and advocate for All Wales People First (the united voice of self-advocacy groups and people with a learning disability in Wales). Lee has a passion for speaking up for people with a learning disability.*

**Balwant Ramphal**

*"I am a retired administrative assistant with the Open University in London, having previously worked with BT, the telecommunications company."*

How to cite this report: Umpleby, K., Roberts, C., Cooper-Moss, N., Chesterton, L., Ditzel, N., Garner, C., Clark, S., Butt, J., Hatton, C., Chauhan, U. (2023) We deserve better: Ethnic minorities with a learning disability and barriers to healthcare. *Race and Health Observatory Report*.

# Abbreviations

**CQC** Care Quality Commission

**DHSC** Department of Health and Social Care

**DNACPR** Do Not Attempt Cardiopulmonary Resuscitation

**EMR** Excess Mortality Rate

**HR** Hazard Ratios

**ICB** Integrated Care Board

**ICD-10** International Statistical Classification of Diseases

**ICU** Intensive Care Unit

**LDE** Learning Disability England

**LeDeR** Learning from Lives and Deaths - people with a learning disability and autistic people

**ONS** Office for National Statistics

**OR** Odds Ratio

**NHS** National Health Service

**MCCD** Medical Certificate of Cause of Death

**MMU** Manchester Metropolitan University

**REF** Race Equality Foundation

**SMRs** Standardised Mortality Ratios

**UCLan** University of Central Lancashire

**UK** United Kingdom

**WHO** World Health Organisation

# Approach to terminology

The NHS Race and Health Observatory has developed five principles that can be followed when talking about race and ethnicity (NHS Race and Health Observatory, 2021). Throughout this report, an active effort has been made to adhere to these principles:

- Where possible, we have been **specific** about the ethnic backgrounds of people that we are referring to.
- We have avoided the use of **acronyms or initialisms** such as 'BME' or 'BAME'.
- We have only used collective terminology where it was necessary and guided by **context**. For example, when analysing data from external data sources with pre-defined ethnicity groupings, or where we are referring to the findings of pre-existing literature.
- We have been **transparent** about the language that we use throughout this report.
- We understand that acceptable terminology changes over time. As such, we will remain **adaptable** to changing our terminology in future work.

Where we are not referring to people from specific ethnic backgrounds, we will use the term **ethnic minority**. When we are talking about people from an ethnic minority background, we are referring to all ethnic groups except 'White British'. Ethnic minority also includes white ethnic minority groupings such as Gypsy, Roma and Irish Traveller groups.

Though the terms '**learning disability**' and 'intellectual disability' are often used interchangeably, from here on we will use the term 'learning disability'. When we talk about the people with a learning disability who have contributed to this project, we use the term '**self-advocate**'.



# Introduction

## What is a learning disability?

---

People with a learning disability may find it difficult to understand new and complicated information, learn new skills and live independently (Department of Health, 2001). It is estimated that there are approximately 1.5 million people with a learning disability in the United Kingdom (UK), of which 1.2 million are estimated to be from England (*Estimates of the Population for the UK, England, Wales, Scotland and Northern Ireland - Office for National Statistics, 2019*).

## What is ethnicity?

---

Ethnicity encompasses a broad range of socially constructed characteristics as well as some biological and genetic variation. In the UK, this has included country of birth, nationality, language spoken at home, national/geographical origin, and religion. Ethnic group, religion and national identity are self-identification measures reflecting how people define themselves, but these can be particularly challenging concepts for some people with a learning disability who may rely on others (family members for example) to define these on their behalf. Skin colour as a method for categorisation of ethnicity is considered unacceptable by some, but forms an important part of the racism that people experience. Thus, ethnicity is a multifaceted concept which can be explored through different lenses.

## What is race and racism?

---

Ethnicity and race are inherently related, and the definition of 'race' in Section 9 of the Equality Act 2010 specifies that 'race includes colour, nationality and ethnic and national origins'. The Equality Act 2010 defines four types of racial discrimination:

1. Being treated worse than another person in a similar situation because of one's race (direct discrimination).
2. When an organisation has a particular policy or practice that puts people from a certain racial group at a disadvantage (indirect discrimination).

3. When someone is made to feel humiliated, offended or degraded in relation to their race (harassment).
4. Someone being treated badly because they have made a complaint of racism (victimisation). In addition, in criminal law, race hate is a range of criminal behaviour where the perpetrator is motivated by hostility or demonstrates hostility towards a person's race.

Racism can be a challenging concept for a person with a learning disability, particularly indirect experiences of racism such as being racially stereotyped, which are often harder to detect than direct racial slurs or hate speech. People with a learning disability have the additional challenge of ableism, which may be easier for them to understand as it will have a more direct impact on their experience, for example, not being given information in a way that they can understand or being spoken to in a patronising, infantilising way.

## Health outcomes in people with a learning disability from ethnic minority backgrounds

There are differences in the prevalence of learning disability among certain ethnic minority populations, for example, higher rates of identification of more severe forms of learning disability have been documented among children of Pakistani and Bangladeshi heritage (Emerson, 2012).

The existing literature has repeatedly reported that people with a learning disability from ethnic minority backgrounds experience significant inequalities in relation to health outcomes. For example, the 2021 Learning from lives and deaths of people with a learning disability and autistic people (LeDeR) report highlighted significant differences in age at death depending on ethnic background. Specifically, only 10% of people reported to LeDeR from an 'Asian/Asian British' background died aged 65 or over in 2021, in comparison to 42% of people from a 'white' background (White et al., 2022).

The COVID-19 pandemic has further highlighted both the extent of the ethnic disparities in health outcomes in the general population and the degree to which this has impacted people with a learning disability. During the first wave of the pandemic, ethnic minority groups experienced higher prevalence, incidence and mortality related to COVID-19 (SAGE, 2020). The Care Quality Commission (CQC) reported an increase of 134% in the number of deaths of people with a learning disability during the first lockdown in the UK (CQC, 2020) with people with a learning disability presenting with more severe symptoms. People with a learning disability were at 56% increased risk of death of COVID-19 following hospitalisation and were dying at a rate 1.44 faster than the general population (Baksh et al., 2021). People with a learning disability were six times more likely to

die of COVID-19, with disproportionate number of deaths (40%) of people from 'Black' and 'Pakistani' communities (Burke & Ong, 2021).

Evidence from the 2019 LeDeR review highlighted that people from an ethnic minority background had a lower median age at death, regardless of the severity of their learning disability (Heslop et al., 2019). Furthermore, in the LeDeR report looking at the deaths that occurred in 2021, being of a 'Black, Black British, Caribbean or African' ethnicity was associated with the highest risk of death at a younger age compared to the 'white' population (White et al., 2022). Coupled with the evidence that people from ethnic minority backgrounds with a learning disability were disproportionately affected by COVID-19 related mortality (Burke & Ong, 2021), it is important to consider why people from these backgrounds experience such levels of health inequalities, and die at a younger age.

## **Barriers to healthcare among people with a learning disability from ethnic minority backgrounds**

---

These inequalities are not limited to health outcomes; a systematic review by Robertson et al. (2019) highlighted multiple barriers for access to healthcare among people with a learning disability from 'South Asian' backgrounds. Reasons for this include a low awareness of specialist services, language barriers, discrimination in service access and a lack of cultural competency within services.

People from ethnic minority groups experience inequalities in relation to access and experiences of healthcare, alongside poorer health outcomes (Kapadia et al., 2022). However, people from ethnic minorities who also have a learning disability can experience inequalities based on both factors, which has been described as a 'double discrimination'. For instance, previous literature has highlighted that people from ethnic minority backgrounds with a learning disability have poorer access to specialist services (Bhaumik et al., 2008; Dura-Vila & Hodes, 2009) and experience barriers to healthcare usage, stemming from a lack of cultural competency within services. Such barriers include a failure to accommodate an individual's spoken language (Hatton et al., 1998; Heer, Rose & Larkin, 2016) and a lack of cultural and religious sensitivity when using services (Bonell, Ali, Hall, Chinn, & Patkas, 2011; Chinn, Hall, Ali, Hassell, & Patkas, 2011; Raghavan & Waseem, 2007).

## What are the gaps we need to explore?

---

As the above evidence highlights, people from ethnic minority backgrounds with a learning disability experience significant inequalities in terms of access, experience and outcomes of care. Given the underrepresentation of this group in research, it is important to dedicate specialised research to understanding the challenges faced by people from ethnic minorities who have a learning disability, and offer evidence-based recommendation and solutions.

Firstly, there is limited evidence reviewing the wider picture of inequalities. This was addressed by conducting a policy review (Section 1) and a review of administrative databases (Section 2), alongside a literature review (Section 3) to explore research conducted in this field thus far. Together these reviews provide a better understanding of the nature of the inequalities faced by those from ethnic minority backgrounds with a learning disability, and the efforts required to address them. The findings of the literature review were taken to a group of 'experts by experience' in a series of experience-based co-design workshops to understand how academic findings relate to lived experience (Part B).

A further aspect of this work was to analyse quantitative data pertaining to ethnicity and learning disability using English health datasets. Firstly, the ethnicity codes of patients on the learning disability register within the Lancashire and South Cumbria Integrated Care Board (ICB) were analysed, as a case study, to assess the completeness and validity of these codes in relation to both the NHS Data Dictionary, and the 2011 census categories (Section 4). In addition to this, a secondary analyses of data generated from the LeDeR programme were conducted, to allow for a more detailed review of the differences in health outcomes and circumstances of death experienced by people with a learning disability from ethnic minority backgrounds (Section 5).

Taken together, insights from the findings have been used to make evidence-based recommendations for reducing inequalities in healthcare experienced by people with a learning disability from an ethnic minority background. A study flow diagram can be found in Appendix 0 (Figure 1).

## Aims of this work

---

The key aim was to address the following questions in relation to ethnic minority population groups who have a learning disability:

- What do we know about the current causes of health inequalities in relation to access, experience and outcomes?

## Introduction

- What are the current policy approaches that aim to address health inequalities in this area?
- To what extent can differences in outcomes be quantified through available data?
- Do insights from answering the above questions fit with lived experience?

## Methodological approach

Understanding the lived experiences of ethnic minority populations, including measuring and comprehending racism within the health and social care sector is challenging and limited, therefore recruitment and design for the planned research was built on best practice (Farooqi et al., 2018).

Six components were conducted as part of the broader review:

1. A review of the existing policies in England pertaining to people with a learning disability from an ethnic minority group.
2. A review of administrative databases with regard to inclusion of data relating to ethnicity and people with a learning disability.
3. A scoping review of the literature on access and experience of health and care services, and health outcomes for people with learning disability from ethnic minorities.
4. Workshops where people with lived experiences can share their thoughts about certain themes which have emerged from the scoping review.
5. Quantitative analyses of ethnicity coding of patients on the learning disability register, focussing on Lancashire and South Cumbria ICB as a case example.

Quantitative analyses of health outcome data generated from the LeDeR programme between 2018-2021.

# Section 1:

## Policy review

The following policy review focuses on relevant national policy documents related to England from 2001 onwards, with some comparative policies from national learning disability strategies in Wales, Scotland and Northern Ireland. Policy documents for England include:

- NHS England and other national policies specifically concerning people with a learning disability (e.g. Building The Right Support) or including components relating to people with a learning disability (e.g. the NHS Long Term Plan)
- DHSC responses to relevant reports and consultations (e.g. responses to LeDeR programme reports and reports from Parliamentary Committees)
- Relevant White Papers (e.g. the Adult Social Care Reform White Paper 2021) and legislation relevant to services for people with a learning disability (e.g. The Care Act 2014).

There are no databases, nor a consistent use of terminology, that allow a text-based systematic review of policy related to health and social care that may be relevant to people with a learning disability from ethnic minority backgrounds. Therefore, a candidate list of policy-relevant documents to be reviewed was produced by the review team in May 2022 and shared with stakeholders for suggested additions and changes. The policy review was also discussed with the review's working group in June 2022, which resulted in some further changes to how we carried out the policy review. The policy review is located in Appendix 1.

Four pieces of legislation were reviewed (Carers and Disabled Children Act 2000; Children and Families Act 2014; Care Act 2014; Down Syndrome Act 2022) – none of them contained information or specific policy direction in relation to people with a learning disability from any ethnic minority group.

Thirty-six government/NHS England/arms length bodies policies and government responses were reviewed, 21 one of which specifically related to people with a learning disability and 15 of which were broader but included people with a learning disability within their scope. From elsewhere in the UK, four national policies focusing on people with a learning disability in Scotland, Wales and Northern Ireland were also reviewed. National statements of policy

from government or arm's length bodies have rarely made explicit mention of inequalities in the lives of people with a learning disability according to ethnicity. Both in England and across the UK, national cross-departmental strategies explicitly focused on people with a learning disability have been more likely to explicitly describe some of the inequalities experienced by people with learning disability and their families from ethnic minority communities. This is also the case in England for recent national policies focused on autistic people. More recently, in England, government responses to LeDeR programme reports have included a recognition of inequalities in the age of death of people with a learning disability across ethnic groups.

Specific policy directions relating to people with a learning disability from ethnic minority communities are also relatively rare. Many policies refer to the Equality Act (2010) in terms of ensuring that the policy should achieve equality according to protected characteristics, although disability is more frequently mentioned as a protected characteristic than race, religion or belief. Policy directions relating to inequalities across ethnic communities experienced by people with a learning disability are largely focused on gaining better information on which to make policy decisions and monitor progress.

## Recommendations

---

Actions for the Department of Health and Social Care and NHS England:

- Production of guidance on how to implement existing policies relating to people with a learning disability, emphasising coproduction approaches, in such a way that the health inequalities for people with a learning disability who are from ethnic minority communities can be addressed.
- The development of future policies should, as standard practice, include advice emphasising coproduction approaches to tackling health inequalities experienced by people with a learning disability from ethnic minority backgrounds.

# Section 2: Administrative datasets review

## Background

---

The aim of this section of the review is to examine routine administrative datasets for England to determine the feasibility of analysing data relating to people with a learning disability by ethnicity, and the feasibility of analysing data using national, regional and more local (e.g. Integrated Care Boards; local authority) geographical footprints.

Appendix 2 gives details on the administrative datasets examined for this review, selected for their potential to provide nationally comprehensive, regularly updated data, relevant to people with a learning disability across ethnic groups. In total, twenty-seven datasets were examined: four related to children and young people, six related to adult social care, six related to health and healthcare, and eleven related to benefits.

## Findings

---

### Consistency of criteria

As different administrative datasets have different histories and purposes, and rely on different information systems, it is unsurprising that learning disability criteria vary widely. The extent to which the populations of people included as people with a learning disability are consistent across administrative datasets is unknown. To a lesser extent this is also an issue for ethnicity criteria used across different administrative datasets. Administrative datasets also need to be carefully evaluated in terms of completeness and accuracy of coding for both learning disability and ethnicity.



## Geography

Although there are differences in the sub-national geographical areas reported across datasets, almost all administrative datasets routinely contain information at regional, system and more local levels. Of the ten datasets relating to children and young people and adult social care, nine contained data at regional and local authority levels. Of the six datasets related to health and healthcare, five contained data at regional and/or more local levels such as Integrated Care Boards, Primary Care Networks or GP practices. All eleven datasets concerning benefits contained data at regional, local authority and parliamentary constituency levels.

## Public availability of learning disability and ethnicity data

Five of the twenty-seven administrative datasets contained publicly available information that compared some aspect of the experience of people with a learning disability across ethnic groups. Examples of the data at a national level that can be extracted from these datasets are contained in Appendix 2:

1. Data on the number and percentage of children with Moderate Learning Difficulty, Severe Learning Difficulty, and Profound and Multiple Learning Difficulty in schools, across 18 ethnicity categories (Appendix 2, Table A). These categories relate to general learning disability – children with a primary need for support relating to specific learning difficulties such as dyslexia, dyscalculia or dyspraxia are included in a separate special educational needs (SEN) category of Specific Learning Difficulty.
2. Data from approximately 5,000 adults with a learning disability drawing on social care, across 'white'/ethnic minority ethnic categories, covering a wide range of demographic factors, experiences of social care services, and self-rated quality of life (Appendix 2, Table B)
3. Data from approximately 1,250 carers of an adult drawing on social care where the carer self-identifies as having a learning difficulty or learning disability, across 'white'/ethnic minority ethnic categories, covering a wide range of carer demographic factors and carer experiences/impacts of caring (Appendix 2, Table C). While this definition is broader than learning disability, it provides valuable information unavailable elsewhere and it would be possible to use more focused definitions of adult carer needs in future editions of the Survey of Adult Carers in England.
4. Data on the number of people with a learning disability and autistic people in mental health/specialist inpatient services, across five ethnic categories (Appendix 2, Table D)

5. Data on the number of people with a learning disability and autistic people in mental health/specialist inpatient services, across five ethnic categories (Appendix 2, Table E)

Three of the twenty-seven datasets do contain information relating to both learning disability and ethnicity, but existing published data and interactive tools do not allow for these to be combined: pupil absences from school, adult social care activity and adult safeguarding.

Eight of the twenty-seven datasets contained information on learning disability, but not on ethnicity. Perhaps the most important of these is the Health and Care of People with Learning Disabilities dataset, extracted annually from GP records in over half of GP practices in England. While patient ethnicity should be recorded routinely within GP records, to date this has not been included in the extraction for the Health and Care interactive data tool.

Four of the twenty-seven datasets contained information on ethnicity, but not on learning disability, and seven datasets contained no information on learning disability or ethnicity. These were largely benefits datasets.

There is considerable potential for administrative datasets to provide substantial ongoing monitoring of the health, experiences, and service responses to people with a learning disability across ethnic groups in England, at national and more local levels. This potential is, at present, considerably under-utilised. Despite challenges relating to data quality and consistency, a programme of work identifying relatively low-cost ways for high priority administrative datasets, that routinely yield such analyses, could be highly cost-effective in generating information for policy and planning nationally and locally.

## Recommendations

---

Actions for NHS England:

- Add ethnicity data to the mandated data collected as part of The NHS Health and Social Care of People with Learning Disabilities dataset, to enable regular and ongoing analyses.
- Review the categorisation of learning disability in existing administrative datasets – moving towards categorisations that disaggregate learning disability and specific learning difficulties.

## Section 2: Administrative datasets review

- Introduce focused questions on health inequalities among people with a learning disability across ethnic groups into the Learning Disability Improvement Standards for NHS Trusts.

Actions for integrated care systems and boards:

- All NHS and care providers should routinely and accurately collect ethnicity data relating to people with a learning disability.

# Section 3: Review of factors that impact access, experience and outcomes

## Introduction

---

This section of the report presents the findings and recommendations derived from a scoping review of the factors in health and care services which impact people with a learning disability from ethnic minority backgrounds

Inequalities in relation to healthcare access, experience and health outcomes among people with a learning disability from ethnic minority backgrounds have been well documented. These existing disparities are not considered to be the consequences of inherent differences between ethnic groups, but rather the social factors of health and the additional barriers of language, cultural incompetency, stigma and racial discrimination.

This scoping review sought to document the existing evidence base which explores the complex health and care factors which impact people from different ethnic minority groups with a learning disability in the UK, in order to better understand how these factors interact to affect the access of health care, experiences of health care and health outcomes.

## Methods

---

Key search terms, of which the details are presented in Appendix 3 (Table A), were entered into three electronic databases (Medline, PsycINFO and Cinahl).

The initial screening of studies consisted of reviewing titles and abstracts to exclude articles that were not within the scope of the review. Subsequently,

articles were taken to full text and were screened according to the inclusion and exclusion criteria detailed in Appendix 3 (Tables B and C). Any disagreement between the reviewers over the eligibility of a particular study were resolved through discussion with a third reviewer.

## Results

The electronic database search generated a total of 7,170 records. Following the removal of 1,400 duplicates, this resulted in 5,770 records which were screened by title and abstract. Five hundred and thirty-one articles were taken to full text, of which 84 were deemed eligible to be included in the review. Ten further reports were included from a manual search. A detailed breakdown of this process is outlined in Appendix 3 (Figure A).

For this review, studies were segregated into those which provide quantitative data and those which provide qualitative/mixed-methods data, and findings in relation to access, experience or outcomes of health care (see Appendix 3, Table D). Each of these studies was assigned a unique identification number ranging from 1-94. Some of these studies are duplicated in the table as they focused on more than one of these three themes.

Studies were included in the theme of 'access' if they reported findings related to how people with a learning disability access care. This includes studies reporting on referrals to different services, studies describing barriers or issues with accessing care or services and studies exploring the experience of people with a learning disability from ethnic minorities or carers in accessing any form of health or social care support from any services.

Studies were included in the theme of 'experience' if they reported findings relating to the lived experience of people with a learning disability from ethnic minorities or families/carers. This includes any aspect of experience and encompasses a broad range of foci which may overlap with the other two themes; for example, studies which describe experiences of accessing care. Experiences of poor care within the theme of 'experience' are not necessarily due to racism, they could be because of ableism or reflect general issues with care provision.

Studies were included in the theme of 'outcomes' if they reported findings related to any health, social or care outcomes. This can include studies reporting on prevalence of health conditions, mortality relating to specific conditions, social outcomes such as crime rates, or mental health outcomes such as prevalence rates of psychiatric disorders, Mental Health Act detainment or challenging behaviours.

Details of the studies included can be found in Appendix 3 (Tables E and F). Thirty-six papers were identified that used qualitative or mixed methods designs (including mixed-methods LeDeR reports which are in Appendix 3 (Table G)). Of these, 21 recruited carers of people with a learning disability to explore their views and experiences. Perspectives of carers are often used where the population of interest is people with severe or profound learning disability. In these cases, carers are used as a way of communicating the needs and experiences of a person with a learning disability who is unable to have their own voice heard through research. Ten qualitative papers recruited people with a learning disability as participants, often this was people with a mild learning disability. Only one paper (Kramer-Roy, 2012) used co-production or participatory action research methods.

The following themes were identified through an iterative process involving the academic team and the working group as areas where further exploration would be helpful through the workshops due to either limited evidence found through the literature review or agreement that this was an area which required further exploration: discrimination; community and family networks; COVID-19; digital access; transitional care; the General Practice (GP) learning disability register; the LeDeR programme. We have also described findings relating to health outcomes (other than COVID-19). The following section reports the findings of the scoping review using the terminology for ethnicity as defined in the studies.

## Discrimination

Two papers were identified that explicitly focused on the concept of discrimination (Ali et al., 2013; Azmi, Hatton, Emerson & Caine, 1997). We also identified other literature which explored matters arguably associated with discrimination, such as a lack of culturally appropriate services and language barriers.

Azmi and colleagues (1997) interviewed 21 adolescents and adults (12 men and 9 women of which 13 were Pakistani, 5 Indian and 3 Bangladeshi) on their views on ethnicity and racism. Many participants (63%) felt that they were treated badly because of their ethnic group, describing racism from people in local neighbourhoods, other service-users and staff. A survey of 54 carers from 'South Asian' communities (Bangladeshi, Pakistani, Indian and East African Asian) identified several barriers to access to services including lack of awareness (Hatton 1998), lack of staff who could speak the same language as the carer; the cultural inappropriateness of existing services in terms of diet, activities and staff provision; and racial discrimination within services. No further detail or discussion is provided in the paper about racial discrimination.

Ali et al (2013) interviewed 29 participants (2 patients from Indian heritage and carer dyads, 3 Pakistani heritage patients and carer dyads, and one Indian carer). Barriers to accessing health care are described due to direct

discrimination (negative staff attitude, failure to treat patients with respect and dignity) and indirect discrimination (lack of staff awareness of patients' needs, and health services failing to accommodate the needs of people). Other barriers described included communication difficulties (staff failing to speak directly with patients, lack of information about availability of services, failure to refer to specialists and provide interpreters). However, no evidence is provided in relation to racism as a factor for the discrimination.

Two studies, which explored experiences within inpatient specialist psychiatric hospitals, mentioned discrimination. One study focused on the views of people with a learning disability (Chinn, Hall, Ali, Hassell, & Patkas, 2011), whilst the other study focused on the views of family members (Bonell, Ali, Hall, Chinn, & Patkas, 2011). Both studies reported that these services were not meeting the cultural needs of patients. In Chinn et al.'s (2011) study, participants described limited opportunities to practice, explore and develop their religious and cultural identities. Additionally, Bonell et al. (2011) reported that there were many examples of cultural needs not being met, for example regarding dietary needs, fasting and being given the opportunity to attend religious services.

## Community and family networks

Bhardwaj (2018) found differences in social network composition and barriers to social inclusion for people with a learning disability from 'white' and 'South Asian' (Indian, Pakistani and Bangladeshi) communities. 'South Asian' participants had more family members in their network while 'white' participants had more service users and staff. The 'South Asian' group were also more likely to have a mixed ethnic network. O'Hara (2003) investigated the experiences of two cultural groups of parents who had a learning disability. All of the Bangladeshi female participants were living at home, and nearly all had an extended network of family support within the home.

The LeDeR report into the deaths of people in 2020 found ethnic differences in living arrangements and main source of support. Specifically, 23% of 'White British' people were reported to live in their own or family home. In comparison, 44% of people of 'Black/African/Caribbean/Black British' ethnicity and 42% of people of 'mixed' ethnicity lived at home. The highest proportion was observed in people from an 'Asian/Asian British' background, with 67% of people residing in the family home. This figure rose to 84% when specifically looking at 'Pakistani' and 'Bangladeshi' people. Furthermore, only 14% of 'White British' people received their main support from a family member or informal carer, in comparison to 49% of people from an 'Asian or Asian British' background.

## Carers

Several papers reported findings relating specifically to the lives of carers and family members from ethnic minority backgrounds of people with a learning disability. Carer stress is reported as an important area of concern for carers' experience, with four studies reporting findings relating to stress levels in carers. For example, Akbar et al. (2020) conducted interviews with 'Pakistani' carers of children with a learning disability and reported that they found stigma around learning disability in their community a significant source of stress leading to strained marital relationships. As this sample was recruited through schools, families already had professional support in place from services, therefore it is not clear how stress affects families without support from services. Nevertheless, other qualitative studies (Hatton et al., 1998; Heer et al., 2015; Huber et al., 2006) reported high stress levels in family members and carers of people with a learning disability. This is supported by findings from quantitative studies which reported high stress levels in carers and suggests that carers from ethnic minority backgrounds may experience higher levels of stress than carers from majority ethnic backgrounds, such as 'white British' carers (Devapriam et al., 2008; Emerson et al., 2004).

There is evidence to suggest higher levels of psychological distress in carers of people with a learning disability from ethnic minorities. Masefield et al. (2022) found that mothers of children with a learning disability had higher levels of distress than other mothers but did not access health services more and were less likely to access healthcare services for psychological distress. Compared to 'white' mothers, 'Pakistani' mothers had lower rates of consultation, suggesting they are less likely to seek support for psychological problems. However, severity of disability in children was not accounted for, which could influence the burden of care and thus levels of strain in mothers.

## LeDeR findings

Five LeDeR reports were included in this review which analysed deaths occurring between 2017-2021. Each of these were mixed-methods reports which provided ethnicity specific analyses in relation to health outcomes. Appendix 3 (Table G), provides an overview of these findings. In each of the reports, less than 10% of death notifications were of people from an ethnic minority background.

The report analysing deaths that occurred in 2021 found that the majority of adults (n=11,138) and children (n=761) with available ethnicity data were from a 'white' background, representing 91% of cases. This compares with 85% of the general population being denoted as 'white' using 2019 census estimates. This may represent an underreporting of deaths of people from ethnic minority backgrounds to the LeDeR programme. For this report, the authors chose not



to analyse median age at death by ethnicity in the main text due to the limited sample size of people from ethnic minority backgrounds.

The report analysing deaths occurring between 2018-2020 found a greater proportion of adults with profound and multiple learning disability were from 'Asian/Asian British' (21%) and 'Black/African/Caribbean/Black British' (14%) ethnic groups, compared those from the 'White British' group (7%). Furthermore, males from an 'Asian/Asian British' background with profound and multiple learning disability had a median age at death of 30 years, whilst males from a 'Black African/Caribbean/Black British' background with profound and multiple learning disability had a median age at death of 33 years. In comparison, for 'White British' males with profound and multiple learning disability who died in 2020, the median age at death was 59 (Heslop et al., 2021). However, interpretation of these estimates warrant caution due to ethnicity not being a mandatory field on LeDeR notifications until 2021.

## COVID-19 health outcomes

Three studies investigated COVID-19 health outcomes noting that being from an ethnic minority background and having a learning disability were two independent risk factors that were associated with increased COVID-19 related outcomes. However, these papers did not specifically analyse the interaction between ethnicity and learning disability (Carey et al., 2021; Cummins et al., 2021; Joy et al., 2020). For example, Carey et al. (2021) found that both being of an ethnic minority (e.g. 'Black' vs 'white' EMR = 2.50, 95% CI 1.97-3.18) and having a learning disability (EMR=8.54, 95% CI 5.99-12.18). were significant risk factors in excess mortality during the first wave of the pandemic, compared to total mortality 2015-19.

In addition, Cummins et al. (2021) investigated risk of hospitalisation, ICU admission and mortality in people with COVID-19. Compared to people of 'white' ethnicity, people of 'Black' ethnicity were at a higher risk of COVID-19 associated hospitalisation (OR = 1.54, 95% CI = 1.13-2.09, p=.006), while people of 'Asian' ethnicity (authors do not provide information on which ethnic minority categories 'Black' or 'Asian' is aggregated from) were at a higher risk of ICU admission (OR = 1.62, 95% CI = [1.01, 2.59], p = .045) and COVID-19 associated death (OR = 1.71, 95% CI = [1.21, 2.42], p = .002). Having a learning disability was a key clinical risk factor for death (OR = 4.75, 95% CI = [1.91, 11.84], p = .001) and was the greatest risk of death associated with a single clinical factor.

Joy et al. (2020) conducted cross-sectional analyses of GP patient records and found that compared with 'white' ethnicity, 'Black' ethnicity was associated with increased mortality (OR = 1.84, 95%CI= 1.33 to 2.54, P = 0.0002). People with a learning disability had a higher odds of mortality OR = 1.97, 95%CI= 1.22 to 3.18, P= 0.0056).

Das-Munshi et al. (2021) assessed excess mortality during the pandemic, however this did not exclusively focus on COVID-19 as an underlying cause of death using prospective data from a large mental healthcare provider in London. By the second quarter of 2020, COVID-19 standardised mortality ratios (SMRs) elevated across all conditions. Specifically, learning disability (n=6,045) had one of the highest SMRs of all conditions (SMR: 9.24 [95% CI: 5.98-13.64]). An increase in mortality risk in the second quarter of 2020 was shown across all ethnic groups, including 'White British', relative to the general population. All-cause mortality trends were similar across ethnic groups.

The LeDeR 2021 report (White et al., 2022) demonstrated that during 2020, considerably higher excess deaths were observed among people from ethnic minority backgrounds (all ethnic minority groups combined), with a rate of 58.2% (95% CI 51.4% – 64.6%), in comparison to people from a 'white' ethnicity who had an excess death rate of 31.3% (95% CI 29.4% – 33.2%). The differences in excess deaths reduced in 2021, with a rate of 17.5% (95% CI 15.63% – 19.06%) for deaths of people with a learning disability of 'white' ethnicity, compared to 20.7% (95% CI 15.63% – 26.56%) for those from ethnic minority groups (White et al., 2022). A regression analysis with COVID-19 as underlying cause of death compared to other causes of death combined found ethnicity was not associated with having COVID-19 as underlying cause of death when other demographic predictor variables, such as age, sex, region and long-term health conditions, were accounted for.

The LeDeR 2020 report found that ethnicity was significantly associated with a greater likelihood of COVID-19 death. 'Asian/Asian British' ethnicity was associated with a three-fold increase in likelihood of COVID-19 death in comparison to people from a 'White British' background. However, this was an unadjusted model which did not control for other demographic variables (Heslop et al., 2021).

## COVID-19 vaccination

A cohort study of 57.9 million patient records in general practice from England highlighted lower vaccination coverage in the first 100 days of the vaccine rollout among certain key groups, including those from ethnic minority backgrounds and those with a learning disability (Curtis et al., 2022). However, no specific analysis was undertaken to assess the interaction between ethnicity and learning disability. In addition, Hatton et al. (2021) interviewed 621 adults with a learning disability and 348 family carers/support workers to investigate willingness of vaccination. The results demonstrated that 87% of interviewees with a learning disability were willing to receive a COVID-19 vaccine, with increased willingness associated with 'white' ethnicity (22% more likely). Surveyed carers were also 30% more willing to receive the vaccine if they were from a 'white' ethnic group. However, in this study, only 5.3% (n=33) of participants with a learning disability and 5.9% of carers (n=22) were from an ethnic minority background.

## Transitional care

Bhaumik et al. (2011) explored carers' perceptions of transitions between services for teenagers with a learning disability. In their analysis, which compared 'South Asian' and 'Caucasian' populations, there were differences in patterns of service use and unmet needs. Specifically, 'South Asian' carers (n=17) reported greater unmet needs in relation to culturally appropriate services and for health, social care and education services in general than 'Caucasian' carers (n=56). However, greater satisfaction was expressed by 'South Asian' carers (43%) in comparison to 'Caucasian' carers (19%) about the transition process. The authors note, however, that this may reflect that a greater proportion of 'South Asian' carers were aware of the transition plan. No other studies explicitly focused on transition of care.

## Learning disability register

Chaplin et al. (1996) conducted a retrospective study of service use in Leicestershire and found that 'Asian' adults (defined by the study as people who originate from the Indian subcontinent, or those who come from East African countries who are of Indian, Pakistani or Bangladeshi descent, or those of Asian origin born in the UK) were underrepresented on the learning disability register with respect to the population.

Nine papers utilised learning disability registers to identify participants with a learning disability, some of these studies conduct secondary analyses on data from learning disability registers (e.g. Tyrer et al., 2020, Tyrer et al., 2007). In addition to being a valuable tool for healthcare professionals, this suggests the learning disability register is also a useful tool for researchers for recruitment of participants with a learning disability.

## Health outcomes

Three papers investigated cases of specific genetic or acquired syndromes in people with a learning disability; these were Micro syndrome (Ainsworth et al., 2001), high myopia and associated conditions (Marr et al., 2001), and Niemann-Pick type C (Winstone et al., 2017). One paper looked specifically at oral health in people with a learning disability from 'Pakistani' backgrounds, finding that oral health was generally poor (Doshi et al., 2009). However, as this study only looked at a small sample (n = 53) of people all from 'Pakistani' backgrounds, it is not known whether these findings would be similar in a sample of people from other ethnic backgrounds.

Dunkley et al. (2017) screened adults with a learning disability for type 2 diabetes and impaired glucose regulation in Leicester and found that 1.3% of 930 people who were screened had type 2 diabetes and 5.2% impaired

glucose regulation. Participants from ethnic minority (n= 182, 20%) backgrounds were four times more likely to have abnormal glucose levels (OR 3.93; 95% CI 2.10 to 7.33). Tyrer et al. (2020) found that people with a learning disability had generally unhealthy lifestyles (low levels of physical activity, high rates of consumption of fizzy drinks and low rates of consumption of fruit and vegetables) which increases risk of type 2 diabetes, and similarly to Dunkley et al., found an association between ethnicity and risk of diabetes, with 'South Asian' groups being at higher risk of type 2 diabetes (OR 2.1; 95% CI 1.08 to 4.41, p = .03). However, socioeconomic deprivation was not accounted for in this analysis, which has been associated with higher risk of type 2 diabetes (Agardh et al., 2011).

Wood et al. (2005) found that ethnicity was associated with measures of mental development in a population of children born extremely preterm. At 30 months, 'African-Caribbean' children had significantly lower mental development scores than 'white' children (Coeff -9.63, 95% CI -13.95 to -5.30, P <0.001). However, there was no significant association between 'African-Caribbean' ethnicity and measures of psychomotor development (Coeff -0.05, 95% CI -4.45 to 4.35, ns). Due to small numbers, there were no reported associations between the measures of development and other ethnic groups.

Verity et al. (2021) looked at cases of progressive intellectual and neurological deterioration. They found similar patterns of disease between 'Pakistani' and 'white' children but more cases of Menkes disease in 'white' children.

Morton et al. (2002) reported prevalence rates of Neurodisability (including severe learning defect, severe and profound hearing loss, partially sighted or registered blind, language disorder, autism and cerebral palsy) among children of 'Mixed' (95% European origin), 'Pakistani' and 'Asian' ethnic groups. There were higher rates of severe and profound hearing loss and severe visual problems in 'Pakistani' children compared to the 'Indian' and 'Mixed' groups. The 'Mixed' ethnic group showed a higher prevalence of language disorder (prevalence/1000 = 4.58, 95% CI 3.80, 5.33) than the 'Indian' (2.28, 95% CI 1.15, 4.49) and 'Pakistani' (1.84 95% CI 0.78, 4.29) groups. Genetic disease as a cause of severe disability was 10 times more common in 'Pakistani' children than any other ethnic group. The sample size in the 'Pakistani' and 'Indian' groups in this study were small compared to the 'Mixed' group (20 and 53 vs 764) which warrants caution when interpreting these findings.

Only one study looked at multimorbidity (two or more long term conditions other than learning disability) in people with a learning disability from ethnic minorities. Although other studies have documented associations between ethnicity and multimorbidity (e.g. Johnson et al., 2017), Tyrer et al. (2019) found that among those with a learning disability, multimorbidity was only independently associated with being female (adjusted OR = 1.82, 95% CI 1.31, 2.53 P <0.001) and having severe/profound learning disability (adjusted OR = 1.95; 95% CI 1.31–2.89; P 0.004). Multimorbidity was associated particularly with sedentary lifestyles (OR =

1.98; 95% CI 1.42–2.77;  $P < 0.001$ ). The sample in this study was 81.2% ‘white’, and due to small numbers in other ethnic minorities, only the ‘South Asian’ group were included in analysis (15.3% of sample). This small sample size may limit the power of the analysis to detect differences between groups.

## Mental health outcomes

Overall, the evidence reviewed is mixed in relation to rates of psychiatric illness amongst those with a learning disability from ethnic minority backgrounds and interpretation is limited by the sample size.

Fifteen studies included findings related to mental health outcomes in people with a learning disability from ethnic minority backgrounds. These outcomes referred to incidences of psychiatric disorders, Mental Health Act detention, and prevalence of problematic behaviours such as physical aggression, in people with a learning disability. Details of these studies can be found in Appendix 3 (Table H).

## Digital access

The literature search did not generate any information pertaining to digital access among people with a learning disability from ethnic minority backgrounds. As digital access was highlighted as an area of concern by members of the working group, the finding of a paucity of literature on the topic prompted the generation of digital access as a theme for discussion in our experience based co-design workshops (see Part B).

## Conclusion

---

The analysis in this scoping review was limited to the literature exploring the health outcomes, access and experience of health and care services for ethnic minorities with learning disability. The review process identified 94 relevant papers. A previous systematic review undertaken by Robertson et al. (2019) identified 23 original articles.

Very little information was identified on physical health outcomes or physical health care, with the identified evidence tending to focus on mental health care, access to specialist intellectual disability services, and inpatient services. There were also limited findings in terms of the themes generated by the workshops, especially relating to transition between adult and child services and digital access.

### Section 3: Review of factors that impact access, experience and outcomes

Much of the literature included in this review focused on 'South Asian' populations, though this research often viewed people from 'South Asian' backgrounds in a homogeneous light and ignored differences that may exist within broad ethnic groups. Information about health inequalities is limited for people from other ethnic minority backgrounds.

The review suggests a lack of research in under-represented groups. For example, only one paper was included in the review that researched the Jewish community and one paper researched Irish Traveller groups. The Increasing Diversity in Research Participation guidance for under-represented groups (NHS England) provides practical suggestions as to how researchers can increase participation (such as providing information in an accessible format and suitable language).

There are several data quality issues that have been identified. For example, research which relies on cohort studies that utilise patient data may not be accurate. Quantitative studies often fail to perform ethnicity specific analyses whereby the interaction between ethnicity and learning disability is investigated. This was particularly a problem for the literature which investigated COVID-19 outcomes.

Researchers should be cautious when grouping participants by ethnicity. Although grouping participants may be a necessary step in order to increase group sizes for analysis, we have found studies often use of broad groupings such as 'Asian' and 'White' without providing further detail. This can make findings relating to ethnicity difficult to interpret. For example, some studies include Chinese ethnic populations within an 'Asian' group, whereas others group Chinese participants as 'other ethnic group'. It is important to be explicit about the heterogeneity within groups by giving examples of the ethnic minorities which are included. For instance, in a qualitative study of the views of cultural needs of Pakistani family members of people with a learning disability, McClimmons et al. (2016) highlighted that despite participants all originating from the Kashmir region of Pakistan, there were different strands of Islam practiced within the group.

Although studies alluded to experiences of people with a learning disability and family/carers that could be driven by discrimination, few discussed findings through this lens. There was very little discussion in the literature about racism. We have interpreted findings relating to lack of culturally appropriate services and language barriers as representing a form of systemic discrimination experienced by people with a learning disability from ethnic minorities and their carers/families. More work is needed to understand the role of racism in the lives of people with a learning disability from ethnic minority backgrounds, including how racism is understood and conceptualised by people with a learning disability.



## Recommendations

---

Actions for integrated care systems and boards:

- Develop inclusive interventions for carers of people with a learning disability from ethnic minority backgrounds that address the range of challenges faced by carers, including those related to their well-being.

Actions for NIHR and other research bodies:

- When commissioning research, NIHR should ensure that researchers are explicit about their approach to describing and grouping ethnicity. Where large, high-level groupings are used for analyses (e.g. South Asian), details should be provided about the specific communities represented (e.g. Pakistani).
- Future research on learning disability should aim to investigate differences in health outcomes by ethnicity.
- Specific research in under-represented groups such as asylum seekers, the Jewish community and Irish Travellers should be commissioned.
- Researchers should use co-production or participatory research designs to utilise the expertise of people with lived experience.
- Whilst recognising the difficulties in access to sufficient data, researchers should perform ethnicity specific (disaggregated) analyses on future research findings to better understand differences in health outcomes between populations.
- Future research should investigate how people with a learning disability from ethnic minority backgrounds understand and conceptualise racism.

# Section 4: Case study of ethnicity recording

## Introduction

---

This section of the report presents the findings derived from a case study of ethnicity codes of patients with a learning disability in GP surgeries. Accurate information concerning the ethnicity of patients is deemed to be an essential prerequisite to reduce inequalities in healthcare usage and health outcomes.

In this case study, we explore the quality of ethnicity codes of patients recorded on the learning disability register held in GP clinical records as part of the Quality Outcome Framework within the Lancashire and South Cumbria Integrated Care Board (ICB). A search was created which included codes correlating to census categories 2001 and 2011, and was then run in GP clinical systems at a practice level. Once the search had been validated in a practice, the search was further tested in a Primary Care Network as part of a quality improvement initiative to improve completeness of ethnicity coding. The search was then approved to be run within each area of Lancashire and South Cumbria ICB (previously recognised as Clinical Commissioning Groups). Some patients had multiple entries but only the latest entry was taken into account.

An overview of the importance of collecting ethnicity data, and of the NHS guidance surrounding the recording of ethnicity, is provided. Using this guidance, the results of quantitative analysis of the validity of the ethnicity codes provided by the Lancashire and South Cumbria ICB are presented.

## Why is it important to capture ethnicity and demographic data?

---

It is important to capture ethnicity data to uncover potential differences in access, experience and outcomes of healthcare, as well as patterns of disadvantage, bias and racism which may otherwise remain hidden.



Currently, the UK is the only European country that collects ethnicity data in the census and across all government bodies (Government Statistical Service, 2015). Ethnic group, religion and national identity are self-identification measures reflecting how people define themselves; but these can be particularly challenging concepts for some people with a learning disability, who may rely on others (e.g. family members) for definition and explanation.

## What is known about the quality of ethnicity data?

The recording of ethnicity information in primary health records was first introduced in 1991 (Mathur et al., 2014). Whilst the coverage of ethnicity recording within primary care has increased over time, there have been concerns over the quality (validity, accuracy and completeness) of such records. Previous research has identified that the ethnicity codes utilised in primary and secondary care are often outdated and there has been evidence of systematic bias in the coding of ethnicity when comparing people from 'white' and ethnic minorities (Scobie, Spencer & Raleigh, 2021). A recent report conducted by the Office for National Statistics (ONS), which examined the consistency of health-related administrative datasets in comparison to the 2011 census, also found differing levels of coding consistency across ethnic groups. For example, the 'White British' category consistently reported the highest level of agreement with the 2011 census (greater than 96%). In comparison, agreement was lowest for 'Any Other ethnic group', with a 15% agreement rate (ONS, 2023).

Accurate ethnicity data are essential for improving the health and healthcare of people from ethnic minority backgrounds with a learning disability. Knowing a patient's ethnicity to the most granular extent is important for informing clinical practice, supporting robust research and improving healthcare provision by allocating resources such as need for interpreter or developing culturally appropriate services including screening programmes, and delivering targeted health information.

However, little is known about the ethnicity coding of people with learning disability from ethnic minority backgrounds. Given the disparities in the health and healthcare experienced by this population, it is crucial to understand and improve the quality of routinely collected ethnicity data.

## How should ethnicity be recorded in health care records?

The ONS asserts that ethnicity is a self-identified construct that should not be ascribed by someone else. The NHS Data Dictionary incorporates the principles outlined by the ONS to record a patient's ethnicity and is based on the 2001 census categories.

Table 1 outlines the national mandatory standard for the collection and analysis of ethnicity data within NHS patient records (NHS Digital, 2022). Best practice for recording ethnicity states that the data "should be collected in agreement and collaboration with the patient and if the ethnicity of a patient is unknown, it should not be assumed or inferred by the provider" (NHS, 2022). Moreover, the ONS guidance recommends that respondents should see all the following categories before recording their ethnicity.

**Table 1.** Extract from the Technical Output Specification; MHS001 and IAPT Table IDS001 - Master Patient Index

Code	Description
A	White - British
B	White - Irish
C	White - Any other White background
D	Mixed - White and Black Caribbean
E	Mixed - White and Black African
F	Mixed - White and Asian
G	Mixed - Any other mixed background
H	Asian or Asian British - Indian
J	Asian or Asian British - Pakistani
K	Asian or Asian British - Bangladeshi
L	Asian or Asian British - Any other Asian background
M	Black or Black British - Caribbean
N	Black or Black British - African
P	Black or Black British - Any other Black background
R	Other Ethnic Groups - Chinese
S	Other Ethnic Groups - Any other ethnic group
Z	Not stated

With the exception of code Z, the ethnic group codes routinely used in the NHS are derived from the categories in the ONS 2001 census. The 2011 census was updated to include separate categories for people from an 'Arab' background or people from a 'White Gypsy' or 'Irish Traveller' background (see Table 2). The 2021 census was further updated to include a separate 'Roma' category under the 'White' ethnic group.

**Table 2.** 2011 census categories

Description	Description
Asian or Asian British - <b>Indian</b>	Black African, Caribbean or Black British - <b>African</b>
Asian or Asian British - <b>Pakistani</b>	Black African, Caribbean or Black British - <b>Caribbean</b>
Asian or Asian British - <b>Bangladeshi</b>	Black African, Caribbean or Black British - <b>Other Black</b>
Asian or Asian British - <b>Chinese</b>	White - <b>British</b>
Asian or Asian British - <b>Other Asian</b>	White - <b>Irish</b>
Mixed or multiple ethnic groups - <b>White and Black Caribbean</b>	White - <b>Gypsy or Irish Traveller</b>
Mixed or multiple ethnic groups - <b>White and Black African</b>	White - <b>Other White</b>
Mixed or multiple ethnic groups - <b>White and Asian</b>	Other Ethnic Group - <b>Arab</b>
Mixed or multiple ethnic groups - <b>Other Mixed</b>	Other Ethnic Group - <b>Any Other</b>

Despite the guidance surrounding ethnicity coding within the NHS, it is likely that several factors affect the quality and consistency of ethnicity data. For example, ethnicity coding is likely to be inconsistent across organisations and care settings as NHS organisations utilise different coding systems which may not be easily collated into the categories outlined in the NHS Data Dictionary. In addition, the guidance for ethnicity coding within the NHS has not been updated since 2001 and thus is not necessarily comparable to the 2011 and 2021 census categories. These issues pose challenges when comparing routinely collected ethnicity data with population estimates.

## Key Findings

### What is the prevalence of learning disability in the Lancashire and South Cumbria ICB?

At the time of data extraction, there were 1,465,131 currently registered patients in practices across the Lancashire and South Cumbria ICB. Overall, 0.57% (n= 8,358) of patients in the Lancashire and South Cumbria ICB were included on their GP practice's learning disability register. There was some variation by area, with the lowest prevalence of 0.48% in North Lancashire and the highest in Chorley and South Ribble of 0.67%, which is highlighted in Table 3.

**Table 3.** The proportion of patients within each area in the Lancashire and South Cumbria ICB that are on the learning disability register.

Area	Prevalence of learning disability (% of patients within ICB that are on the LD register)
<b>Blackpool</b>	0.51%
<b>Blackburn with Darwen</b>	0.51%
<b>Chorley and South Ribble</b>	0.67%
<b>Preston</b>	0.63%
<b>West Lancashire</b>	0.50%
<b>East Lancashire</b>	0.60%
<b>North Lancashire</b>	0.48%

The prevalence of learning disability within the Lancashire and South Cumbria ICB was compared to general population estimates of ethnicity. In our analysis, we used population estimates derived from the 2021 census. This allowed us to compare ethnic group breakdowns between the general population and patients recorded on the learning disability register.

For the purposes of our analysis, we collated census data from three areas within the North West to enable comparisons to the Lancashire and South Cumbria ICB. Specifically, we combined data from Lancashire, Blackburn with Darwen and South Lakeland. This yielded a total sample of 1,494,642 people.

According to this collated census data, the population is predominantly 'White' (86.6%), with ethnic minorities representing the remaining 13.4%. Table 4 provides a breakdown of these proportions, alongside a comparison to the ethnic breakdown of patients on the learning disability register within the Lancashire and South Cumbria ICB. To enable this comparison, we categorised valid ethnic codes of patients (n=5677) on the learning disability register into 5 categories: 'White', 'Asian', 'Mixed', 'Other' and 'Black'.

There was some variation in ethnic breakdowns when comparing the ICB and census data. There was a significantly higher proportion of patients recorded on the learning disability register within the Lancashire and South Cumbria ICB that were from an Asian background, in comparison to general population estimates for that area. However, it is important to note that only 73.6% of ethnicity recordings could be collated into the above 5 categories.

**Table 4.** Ethnicity breakdowns using 2021 Census data\* in comparison to the Lancashire and South Cumbria ICB data.

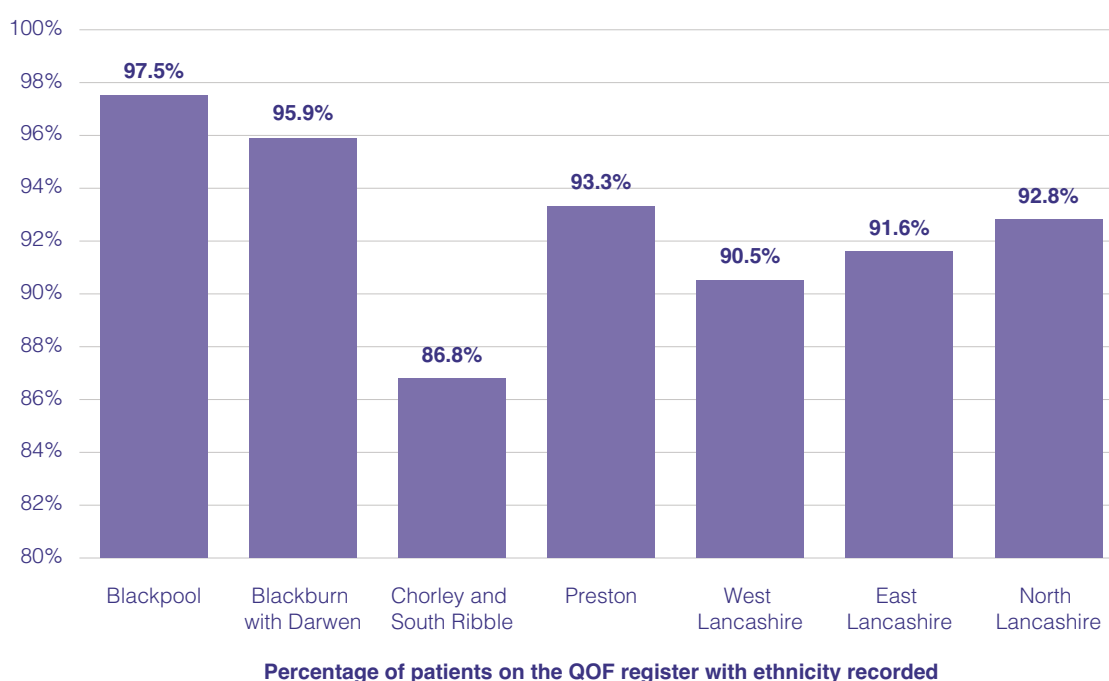
Ethnicity	Proportion (n) in ONS Data	Proportion (n) in ICB Data
White	86.6% (1,294,012)	81.7% (4638)
Asian	10.4% (156,021)	15.9% (905)
Mixed	1.6% (23,677)	1.2% (70)
Other	0.8% (11,296)	0.8% (44)
Black	0.6% (9,636)	0.2% (20)

\* This uses collated ONS data across Lancashire, Blackburn with Darwen and South Lakeland.

## What proportion of patients on the learning disability register have a recorded ethnicity?

We found that, overall, the proportion of records containing an ethnicity was high, with 92.6% of the 8,268 patients within the ICB on the learning disability register having a recorded ethnicity. Figure 1 shows the breakdown of these percentages, separated by each historical Clinical Commissioning Group (CCG) area which now form the ICB.

**Figure 1.** The proportion of patients on the QOF learning disability register with ethnicity recorded

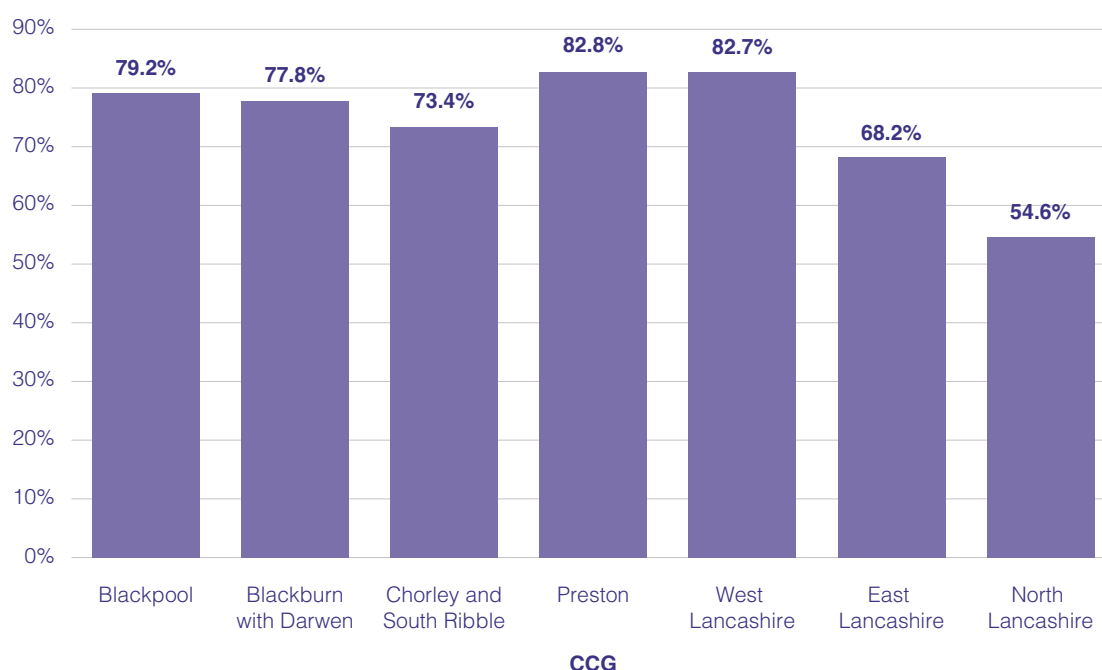


## To what extent is ethnicity coding valid when comparing to the NHS Data Dictionary?

We analysed the validity of ethnic category coding across the ICB by comparing a patient's recorded ethnicity to the codes outlined in the NHS Data Dictionary (Table 1). It is important to note that whilst the codes 'Not stated' or 'Unknown' are permitted for use by the NHS Data Dictionary and are perhaps being used as evidence for 'completeness' of data collected, these codes do not allow for analysis of ethnicity data in a meaningful manner.

Overall, across the Lancashire and South Cumbria ICB, 73.4% (n=5,662) of people on the learning disability register with a recorded ethnicity could be categorised using the NHS Data Dictionary. As graphically illustrated in Figure 2, there was variation between each area. North Lancashire had the lowest proportion of ethnic codes that could be classified according to the NHS Data Dictionary, representing only 54.6% of patients. In comparison, the highest rates of validity were observed across Preston and West Lancashire, where approximately 83% of ethnicity codes were valid according to the NHS Data Dictionary.

**Figure 2.** The proportion of patients with valid ethnicity codes using the NHS Data Dictionary, separated by CCG



## Most frequently recorded ethnic categories

Of the 5,662 patients across the ICB whose recorded ethnicity could be collated into the NHS Data Dictionary codes, the five most frequently reported ethnic categories were:

- White British (78.4%, n=4,441)
- Pakistani (9.4%, n=534)
- Indian (4%, n=227)
- Any other White background (2.5%, n=140)
- Any other Asian background (1.4%, n=81)

Combined, 1.1% (n=61) of patients had an ethnicity code listed as 'Not stated' or 'Unknown'.

## To what extent is ethnicity coding valid when comparing to the 2011 census?

The ethnic categories outlined in the 2011 census (Table 2) were compared with the ethnicity codes of patients on the learning disability register within the ICB. Whilst 'Not stated' and 'Unknown' are valid NHS Data Dictionary codes, these are not valid categories on the 2011 census. Moreover, the 2011 census captures two additional ethnic backgrounds, namely 'Arab' and 'Gypsy or Irish Traveller'.

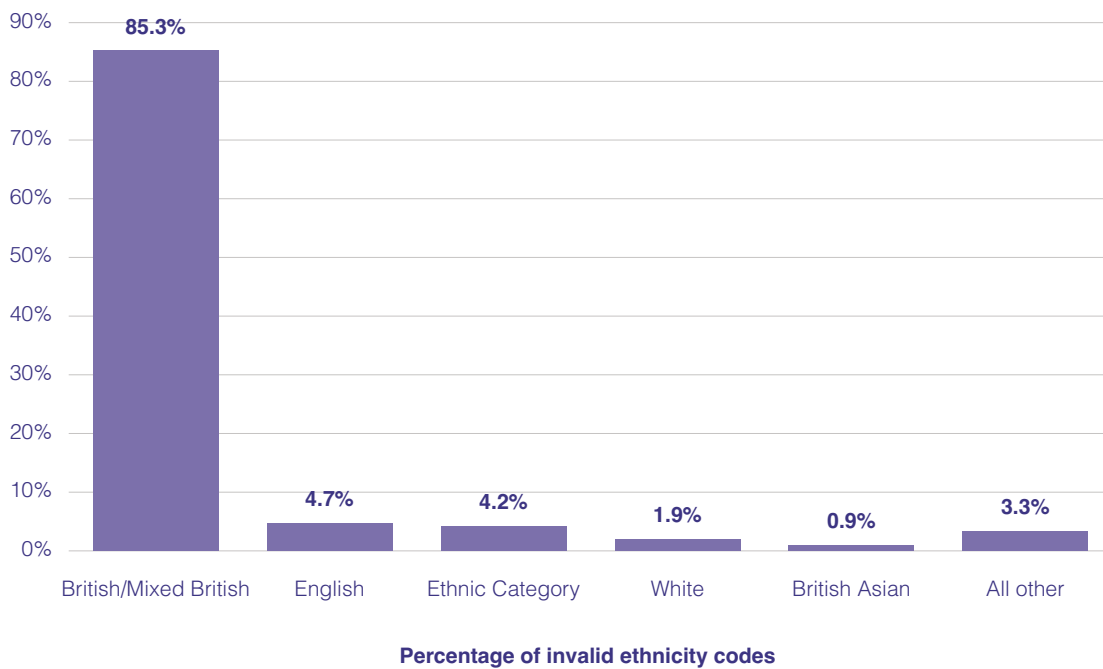
As the ethnicity codes used in the NHS Data Dictionary and 2011 census are largely similar, there was little variation in the proportion of valid codes. Specifically, from a total of 7,717 records, 72.7% (n=5,608) of these could be categorised using the 2011 census. The additional 'Arab' ethnic category in the 2011 census accounted for 0.1% (n=7) of patients across the ICB. Zero patients were recorded as being from a 'Gypsy or Irish Traveller' background.

Therefore, 2,109 (27.3%) ethnicity codes of patients from across the ICB could not be categorised using the 2011 census. The majority of these patients were recorded as 'British or Mixed British', representing 83.1% of these cases.

## What were the most common codes that could not be classified?

A total of 26.6% (n=2,055) of ethnicity recordings could not be classified according to the NHS Data Dictionary. The majority of these patients were recorded as 'British or Mixed British', and importantly, accounted for 22.7% (n=1,753) of the 7,717 patients across the ICB with recorded ethnicity data. Figure 3 displays a graphical illustration of the top 5 most frequently reported invalid ethnicity codes.

**Figure 3.** The top 5 most frequently recorded invalid ethnicity codes



Whilst these were minimal, other invalid ethnicity codes, as per the NHS Data Dictionary and the 2011 census, were used. Such codes related to a person's religious background, such as 'Muslim' and 'Sikh'. Other codes described a person's nationality, such as 'Polish' or 'Greek'. Finally, broad codes such as 'Black British' or 'British Asian' were used which ignored specific ethnic backgrounds.

We were unable to ascertain further detail on the ethnicities represented by codes such as 'British/Mixed British'. This is because the dataset we accessed only included the latest recorded ethnicity code for patients, therefore it was not possible to review previous records of ethnicity to investigate further.



## Conclusion

---

The above analyses have highlighted significant issues in relation to the ethnicity coding of patients on the learning disability register within the Lancashire and South Cumbria ICB. A seemingly high proportion of patients have an ethnicity recorded, however, on closer analysis, just over 25% of these ethnicity codes are not valid according to either the NHS Data Dictionary, or the 2011 census. Over 20% of all patients on the learning disability register within the ICB were categorised as being from a 'British or Mixed British' background. It was not possible to ascertain differences in coding of ethnicity by gender or age from the data extracted, though this should be considered for future analysis.

These issues pose challenges for both research and clinical practice. Much of the research in the learning disability field which examines differences in health outcomes relies on data generated from patient records. However, given the issues with the quality of ethnicity coding, it is difficult to ascertain true differences in outcomes between people of different ethnic backgrounds.

Furthermore, as there are differences in health outcomes and risks between ethnic groups, it is crucial, particularly from a clinical perspective, to have an accurate understanding of a patient's ethnicity. Having an accurate understanding of a person's ethnicity is essential for improving healthcare provision by allocating resources, such as recording whether a person requires an interpreter, improving access to screening programs and delivering targeted health information in an accessible format.

One potential explanation for this low-quality ethnicity data stems from the lack of NHS guidance surrounding the collection of ethnicity data. Issues with the NHS guidance are two-fold. First, there is no mandated procedure for recording ethnicity, as NHS organisations are permitted to utilise different coding systems for the purpose of recording patient ethnicity. Second, the guidance for ethnicity coding within the NHS is likely outdated, as it has not been updated since 2001. To alleviate these issues with ethnicity coding, we propose that adjustments should be made to improve data quality at the source of collection. Specifically, the NHS Data Dictionary should be updated to be reflective of the 2021 census categories, which will ensure that the codes are inclusive of different ethnic backgrounds. Moreover, guidance needs to be provided for health and care staff which includes protocols around the enquiry and recording of a patient's ethnicity. The accuracy of the data collection process should be audited by NHS England.

ICB's should also ensure that updated guidance on ethnicity coding is implemented across their areas to ensure best practice. Individual GP practices play a key role in ensuring that these guidelines are adhered to.

## Section 4: Case study of ethnicity recording

Whilst for this report we only considered the latest ethnicity entry for each patient, it is possible that some ethnicity data were collected a long time ago. It would be beneficial for GP surgeries to re-record ethnicity information for people on the learning disability register. One feasible way that this may be achieved is to update this information as part of an annual health check.

There may be difficulties in adhering to a standardised ethnicity coding system due to the complex and multifaceted nature of ethnic identification. Thus, it would be beneficial to present a person with a standardised list of ethnic categories to choose from, to minimise instances of inaccurate ethnicity codes.

## Recommendations

---

Actions for NHS England:

- Develop co-produced guidance for primary care staff on obtaining self-disclosed ethnicity information from patients with a learning disability, and accurately recording this information in medical records.
- The NHS Data Dictionary to be implemented in all NHS commissioned services and be updated in line with the 2021 Census categories.
- NHS data systems should only use categorisations of ethnicity that are in-line with the latest NHS Data Directory definitions.

Actions for integrated care systems and boards:

- The quality (completeness, validity, and accuracy) of ethnicity coding for people with a learning disability should be validated in health care records by integrated care boards.

# Section 5: LeDeR Data Analysis

## Introduction

---

This section of the report presents the findings and recommendations derived from the analysis of data generated from the 'Learning from lives and deaths – people with a learning disability and autistic people' (LeDeR) programme. Data from 2018-2021 have been aggregated to allow for a more detailed review of the differences in health outcomes and circumstances of death experienced by people with a learning disability from ethnic minority backgrounds.

Alongside disparities in healthcare access and usage, people with a learning disability from ethnic minority backgrounds experience significant inequalities in relation to health outcomes. Previous LeDeR reports have repeatedly documented these inequalities; for example, the 2021 LeDeR report highlighted significant differences in age at death depending on ethnicity. Specifically, only 10% of people reported to LeDeR from an 'Asian or Asian British' background died aged 65 or over in 2021, in comparison to 42% of people from a 'white' background (White et al., 2022).

For the current report, we sought to quantify health outcomes using data generated from the LeDeR programme of people who died between 2018-2021. The following statistics do not capture all the people with a learning disability who have died during this period as notifying a death to LeDeR is not mandatory. The data from 2018-2021 has been aggregated as only a small number of deaths reported each year are of people from ethnic minority groups and broader categories of ONS classifications such as 'Asian/Asian British' (Indian, Pakistani, Bangladeshi, Chinese and any other Asian background) was necessary to allow meaningful analysis.

In order to demonstrate a possible underreporting of deaths of people from ethnic minorities to the LeDeR programme, we sought to compare external datasets to the LeDeR data documenting COVID-19 mortality in ethnic minority populations. However, it became clear that there is a lack of research examining the differences in mortality outcomes in people with a learning disability by ethnicity. In order to better understand the disparities in health outcomes, it is essential for researchers to perform ethnicity specific analyses in future research.

## Data

---

Two sources of LeDeR data were used in this analysis. Firstly, we used notification data, which is the data submitted by the person who notifies the LeDeR programme of a death. Anyone can notify the programme of a death online, though most notifications are from health professionals. Notifications include basic demographic information and brief details of the circumstances of death, such as where the death occurred and if there are concerns about quality of care.

Notifications are examined by reviewers and if the deceased is confirmed to have a learning disability or autism, an initial review is conducted. Initial review data includes information gathered from the family of the deceased, professionals involved in their care and clinical records. Initial review data was used to analyse circumstances of death such as DNACPR recommendations and causes of death.

## Notifications of Death

---

Ethnicity was not a mandatory field when reporting a death to the LeDeR programme until 2021. As such, a total of 756 notifications of deaths between 2018-2020 were excluded from the following analyses as they did not contain ethnicity information. The following descriptive statistics are based on a total sample of 11,899 notifications of deaths to the LeDeR programme between 2018-2021 that had available ethnicity data. Of these deaths, 10,812 (90.9%) were people denoted as 'white', and 1,087 (9.1%) were people of an ethnic minority background.

Table 5 provides a breakdown of notifications to the LeDeR programme between 2018-2021, separated by year and ethnicity. People denoted as 'Mixed' ethnic group accounted for 4% of notifications to the LeDeR programme between 2018-2021<sup>1</sup>. People denoted as 'Black, Black British, Caribbean or African' or 'Asian or Asian British' accounted for 2.2% and 1.7%, respectively. The lowest proportion of notifications to the LeDeR programme was observed for people whose ethnicity was denoted as 'Other', reflecting 1.3% of notifications. This notification rate is inconsistent with general population estimates of ethnic minorities in England and prevalence in GP learning disability registers in our analysis (see Table 4, page 37 of this report).

---

<sup>1</sup> The 2021 LeDeR report categorises ethnicity using the 'broad' ethnic categories outlined in the 2021 census. As such, the 'Mixed' ethnic background includes people from the following Mixed or multiple ethnic groups: 'White and Black Caribbean', 'White and Black African', 'White and Asian', and 'Any other Mixed or multiple ethnic background'.

## Section 5: LeDeR Data Analysis

In comparison to 2020, a threefold increase in notifications to the LeDeR programme was observed among people denoted as ‘Asian or Asian British’ in 2021. One potential explanation is that as people from ‘South Asian’ backgrounds were disproportionately affected by COVID-19 mortality (ONS, 2020). However, it is difficult to determine a specific explanation as we do not know the leading cause of death of all of the people who were notified to LeDeR in 2021, as this utilises review data which may not be completed prior to the data cut-off point for the LeDeR main report analysis.

**Table 5.** The total number of notifications to LeDeR, separated by year and ethnicity.

<b>Ethnic Group</b>	<b>2018</b>	<b>2019</b>	<b>2020</b>	<b>2021</b>	<b>Total</b>	<b>% of notifications</b>
White	2322	2497	3163	2830	<b>10812</b>	<b>90.9</b>
Mixed	88	121	180	83	<b>472</b>	<b>4.0</b>
Black, Black British, Caribbean or African	52	54	87	65	<b>258</b>	<b>2.2</b>
Asian or Asian British	40	25	35	98	<b>198</b>	<b>1.7</b>
Other	26	48	57	28	<b>159</b>	<b>1.3</b>

The proportion of LeDeR notifications by region and ethnicity was compared to general population estimates of ethnicity. In our analysis, we used population estimates derived from the 2021 census. This allowed us to compare ethnic group breakdowns between the general population and the people with a learning disability who had been notified to LeDeR in 2021. Table 6 provides a breakdown of these proportions. For both data sources, ethnic codes were categorised as ‘White’, ‘Asian’, ‘Mixed’, ‘Other’ and ‘Black’, which enabled a direct comparison.

**Table 6.** The proportion of notifications to LeDeR in 2021, by region and ethnicity, compared to 2021 Census data

	Source	Ethnicity Grouping				
		Asian or Asian British	Black, Black British, Caribbean or African	Mixed	Other	White
<b>South East</b>	LeDeR	1.6%	0.0%	0.7%	1.6%	96.1%
	ONS	7.0%	2.4%	2.8%	1.5%	86.3%
<b>South West</b>	LeDeR	1.8%	0.8%	1.6%	0.8%	95.1%
	ONS	2.8%	1.2%	2.0%	0.9%	93.1%
<b>London</b>	LeDeR	6.3%	12.3%	9.0%	3.0%	69.3%
	ONS	20.7%	13.5%	5.7%	6.3%	53.8%
<b>Midlands</b>	LeDeR	4.0%	1.7%	3.5%	1.0%	89.9%
	ONS	10.7%	3.6%	2.7%	1.7%	81.4%
<b>East of England</b>	LeDeR	1.7%	1.7%	1.5%	0.0%	95.1%
	ONS	6.4%	2.9%	2.8%	1.4%	86.5%
<b>North West</b>	LeDeR	4.2%	0.5%	1.4%	0.7%	93.3%
	ONS	8.4%	2.3%	2.2%	1.5%	85.6%
<b>North East</b>	LeDeR	2.8%	0.6%	2.4%	0.2%	94.1%
	ONS	3.7%	1.0%	1.3%	1.0%	93.0%

*\*the Midlands ONS data collates data across West Midlands and East Midlands.*

There was some variation in ethnic breakdowns when comparing the LeDeR and census data. For the most part, there was a significantly higher proportion of people notified to LeDeR from a 'white' background, in comparison to general population estimates for that region. For example, 93.3% of people reported to LeDeR in 2021 from the North West were denoted as 'white', despite only 86.5% of the general population being from a 'white' background in the North West. However, there were regional differences; for example a higher proportion of people reported to LeDeR in 2021 from London were from ethnic minority groups.

## Median Age at Death

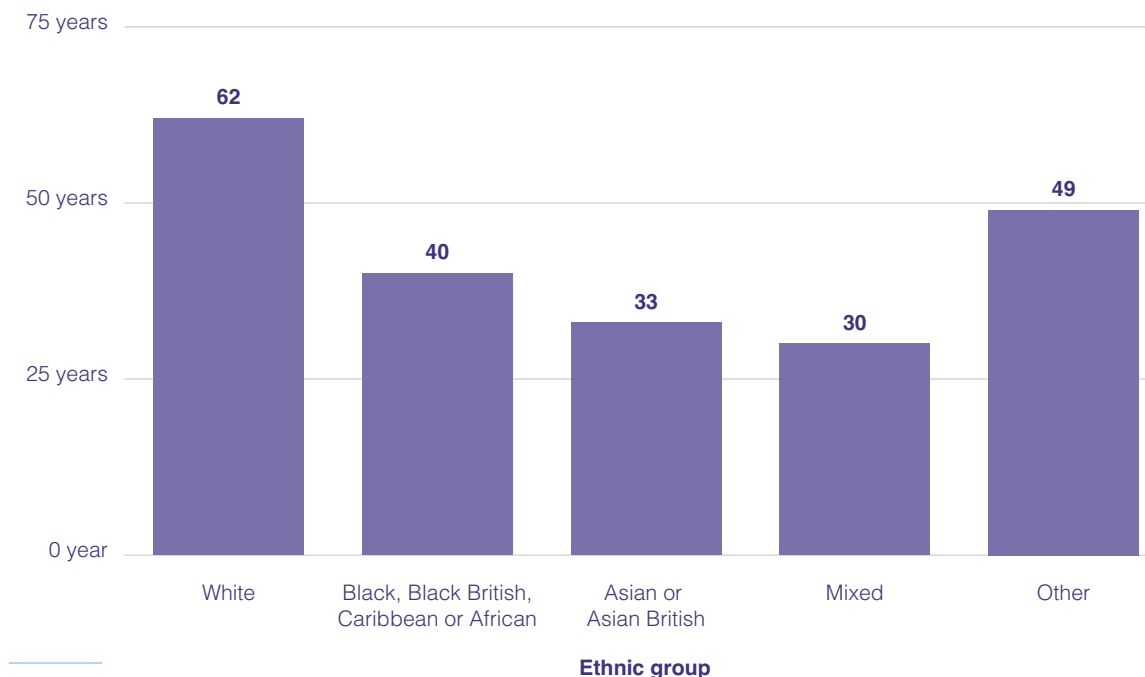
This section reports on the median age at death for people with a learning disability from ethnic minorities compared to people from a 'white' background with a learning disability who died for the period between 2018 and 2021<sup>2</sup>.

When considering median age at death and ethnicity, it is apparent that people from ethnic minorities have a lower age at death than those denoted as 'white'. However, the number of people who died who were denoted as being of an ethnic minority background were small, so the findings must be interpreted with caution.

There was a considerable difference in the median age at death for people denoted as 'white' compared to ethnic minority groups. 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'.

Figure 4 provides a breakdown of the median age at death for the different ethnic backgrounds recorded by LeDeR between 2018-2021. The lowest median age at death was observed for people denoted as 'Mixed' ethnic group, who died at 30 years old (min=4; max=86). The highest median age at death was observed for people denoted as 'Other' ethnic group, with an average age at death of 49 years (min=5; max=96).

**Figure 4.** Median age at death for notifications to LeDeR between 2018-2021, separated by ethnicity.



<sup>2</sup> The median age at death is the age at which exactly half the deaths were deaths of people above that age and half were deaths below that age.

Table 7 provides a further breakdown of median age at death, separated by ethnicity and gender for adults. The median age at death in the tables below may not be reflective of the overall median age at death, as the above figures include children who have died. The table below only includes people over the age of 18 who have died.

**Table 7.** Median age at death by ethnicity and sex for adults over 18, 2018-2021.

Ethnic Group	Sex	Total number of deaths	Median age at death
Asian or Asian British	Female	63	44
Asian or Asian British	Male	79	43
Black, Black British, Caribbean or African	Female	80	50.5
Black, Black British, Caribbean or African	Male	123	50
Mixed	Female	144	46.5
Mixed	Male	187	39
Other	Female	62	61.5
Other	Male	60	54
White	Female	4453	62
White	Male	5883	63
-	Other	*	*

\* number of deaths is fewer than 10

## Circumstances of Death

This section reports the circumstances of death of people with a learning disability, regarding ethnicity. We have drawn on data from LeDeR initial reviews which were completed between 2018 and 2021.



Analysing the contextual information collected during initial reviews allows us to describe the circumstances in which people died. Below, we report: where people died, whether a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) recommendation was made prior to death, and whether a DNACPR recommendation was followed correctly.

## Place of Death

Information about place of death was available for 10,403 people who died between 2018-2021. Only 9% (n=883) of these deaths related to people from an ethnic minority background. Table 8 shows that the highest proportion of hospital deaths was recorded for people from an ethnic background denoted as 'Other', representing 73% of deaths. People from this ethnic category also had the highest proportion of deaths recorded as occurring outside of hospital or a person's usual place of residence. People denoted as 'white' or 'Mixed' had the highest proportion of deaths which occurred in their usual place of residence (34.3% and 32.0%).

**Table 8.** The proportion of people who died in hospital, their usual place of residence or elsewhere between 2018-2021, separated by ethnicity.

Ethnicity	Hospital	Usual Place of Residence	Other
Asian or Asian British	65.3%	28.1%	6.7%
Black, Black British, Caribbean or African	69.9%	25.4%	4.7%
Mixed	62.5%	32%	5.3%
Other	72.9%	21.3%	7.7%
White	60.1%	34.4%	5.5%

## Deaths with 'Do Not Attempt Cardiopulmonary Resuscitation' (DNACPR) recommendations

Information relating to whether a person had a DNACPR recommendation in place at the time of their death was available for 7,459 people, of which 92% were white. Table 9 shows that people denoted as 'white' had the highest proportion of DNACPR recommendations in place at the time of death (73.0%). In contrast, the lowest proportion of DNACPR recommendations in place at

the time of death was observed for people denoted as 'Black, Black British, Caribbean or African' (51.5%).

**Table 9.** The proportion of people with a DNACPR recommendation in place at the time of death between 2018-2021, separated by ethnicity.

DNACPR decision in place at the time of death	Asian or Asian British	Black, Black British, Caribbean or African	Mixed	Other	White
Yes	59.2%	51.5%	57.1%	55.9%	73%
No	40.8%	48.5%	42.9%	44.1%	27%
Total No.	49	136		102	6,885

The proportion of deaths where the reviewer thought that the DNACPR recommendation was made correctly was similar across each ethnicity (see Table 10).

**Table 10.** The proportion of adults who died with a DNACPR recommendation in place at the time of their death, for whom documentation was completed and/or followed between 2018-2021, separated by ethnicity.

DNACPR decision correctly completed and followed	Asian or Asian British	Black, Black British, Caribbean or African	Mixed	Other	White
Yes	75.9%	71.4%	69.3%	70.2%	70.5%
No	0%	4.3%	3.7%	5.3%	4.8%
Not known by reviewer	24.1%	24.3%	27%	24.6%	24.7%
Total No.	29	70	163	57	5,024

## Determination of underlying cause of death

When someone dies, a doctor who was involved in their care completes a Medical Certificate of Cause of Death (MCCD) which indicates the sequence of conditions which lead to their death. This includes the underlying cause, defined

by the World Health Organisation (WHO) as the disease or injury that led to death or the circumstances of the accident or violence that produced the fatal injury.

The underlying cause of death is usually taken from the lowest completed line of part one of a person's death certificate and assigned one of around 14,200 codes according to the International Statistical Classification of Diseases (ICD-10). Underlying cause of death can also be a judgement from the coroner or the ONS based on WHO guidelines. LeDeR initial reviews include information from the MCCD which is the data we used for this analysis. For ease of interpretation, LeDeR report data groups ICD-10 codes by leading cause of death. This involves using an internationally recognised list of prevalent conditions to allow for comparison between populations.

### Leading cause of death by ethnicity 2018-2019

Due to the small numbers of people in the data from ethnic minority groups, we have grouped findings across years. When interpreting findings, it is important to consider that despite grouping data the number of people in ethnic minority groups is still small. We have split findings into 2018-2019 deaths and 2020-2021 deaths to account for the role of COVID-19 which emerged as a leading cause of death in 2020. Deaths reported here are drawn from data of 8,249 adults over the age of 18 who had their death reviewed by LeDeR and had ethnicity and leading cause of death information recorded.

Table 11 shows the leading causes of death for people with a learning disability who died in 2018-2019 by ethnic group with the number one leading cause of death in bold. The most common cause of death for people denoted as 'white' was cancer, closely followed by congenital malformations, deformations and chromosomal abnormalities. There was insufficient data to report leading cause of death for people denoted as 'Mixed' ethnic group. Cerebral palsy and other paralytic syndromes were the leading cause of death for people denoted as 'Black, African, Caribbean or Black British'. Influenza and pneumonia were the most common leading cause of death for people denoted as 'Asian or Asian British'. For people denoted as 'Other', cancer was the leading cause of death.

**Table 11.** The percentage of deaths of adults who received a LeDeR review and had cause of death and ethnicity information recorded by leading cause of death, 2018-2019.

Leading cause of death	Asian or Asian British % of causes of death (n)	Black, Black British, Caribbean or African	Mixed	Other	White
Congenital malformations, deformations and chromosomal abnormalities	*	10.6% (10)	*	13.5% (5)	17.8% (630)
Cancer	15.5% (9)	13.8% (13)	*	<b>16.2% (6)</b>	<b>17.9% (631)</b>
Influenza and pneumonia	<b>17.2% (10)</b>	16% (15)	*	*	13.8% (489)
Ischaemic heart diseases	*	6.4% (6)	*	13.5% (5)	6.3% (224)
Cerebrovascular diseases	*	5.3% (5)	*	*	5.8% (204)
Dementia and Alzheimer's disease	*	*	*	*	5.6% (197)
Cerebral palsy and other paralytic syndromes	*	<b>21.3% (20)</b>	*	*	4.9% (172)
Epilepsy and status epilepticus	*	5.3% (5)	*	*	4.4% (154)

## Leading cause of death by ethnicity 2020-2021

Table 12 shows the leading causes of death for people with a learning disability who died in 2020-2021 by ethnic group with the number one leading cause of death in bold. For all ethnic groups, COVID-19 was by far the most common leading cause of death. Cancer was the second leading cause of death for people denoted as 'white', 'Black, African, Caribbean or Black British', 'Asian or Asian British' and 'Other' ethnic groups. Again, the number of people in ethnic minority groups was small so this warrants caution during interpretation.

Section 5: LeDeR Data Analysis

**Table 12.** The percentage of deaths of adults who received a LeDeR review and had cause of death and ethnicity information recorded by leading cause of death, 2020-2021.

Leading cause of death	Asian or Asian British	Black, Black British, Caribbean or African	Mixed	Other	White
COVID-19	<b>31.3% (25)</b>	<b>37.7% (52)</b>	<b>59.7% (37)</b>	<b>28.8% (17)</b>	<b>25.7% (1071)</b>
Congenital malformations, deformations and chromosomal abnormalities	8.8% (7)	6.5% (9)	*	*	11.5% (478)
Cancer	15% (12)	12.3% (17)	*	10.2% (6)	12.6% (524)
Influenza and pneumonia	7.5% (6)	8% (11)	*	8.5% (5)	8.2% (340)
Ischaemic heart diseases	*	*	*	10.2% (5)	5.5% (228)
Cerebrovascular diseases	6.3% (5)	3.6% (5)	8.1% (5)	*	4.6% (191)
Dementia and Alzheimer's disease	*	*	*	*	4.4% (183)
Cerebral palsy and other paralytic syndromes	*	8.7% (12)	*	*	4.7% (196)
Epilepsy and status epilepticus	*	5.8% (8)	*	*	2.6% (108)

## Modelling the Effects of Ethnicity on Age at Death

### Background

Previous LeDeR annual reports have investigated various factors that may influence a person's age at death, including ethnicity. For example, in the LeDeR report looking at the deaths that occurred in 2021, ethnicity was found to be a significant predictor of age at death (White et al., 2022). Specifically, it was found that being denoted as 'Black, Black British, Caribbean or African' was associated with the highest risk, meaning that people from these ethnic groups were more likely to die at a younger age compared to the white population.

### Analysis

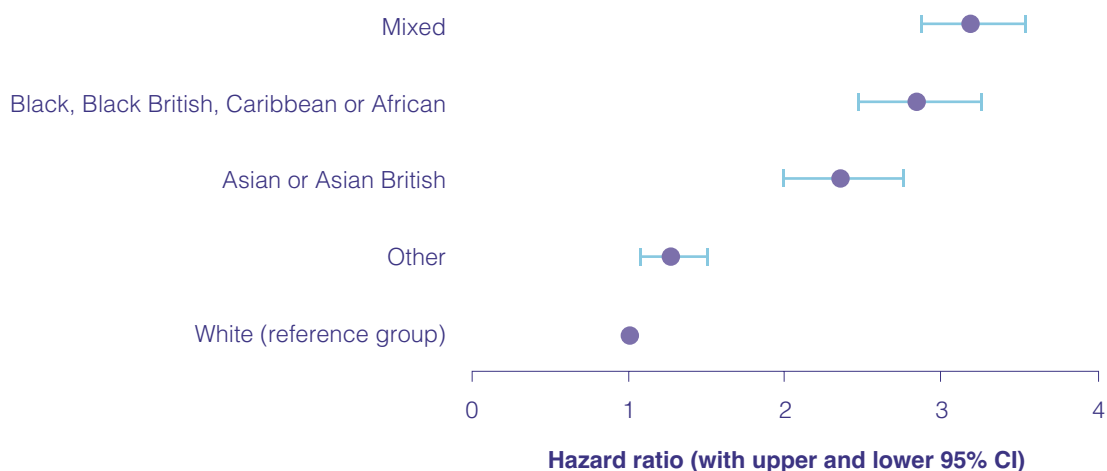
In this report, we have employed a similar method of statistical analysis that was used in the 2021 LeDeR report. A Cox proportional hazard model was used to investigate the effect of ethnicity as a predictor variable on age at death. Unlike the previous LeDeR report which focused solely on 2021 deaths, here we model the data relating to the 11,138 deaths of adults that had ethnicity data available for the period between 2018-2021.

We fitted a model which had ethnicity as the predictor variable to estimate the effect on age at death. No other variables were included in the model. In the model, 'white' ethnicity was the reference group. The results of the analyses are expressed as hazard ratios (HR), with a HR of more than one indicating an increased risk of a younger death compared to those denoted as 'white'.

### Findings

The model found that being from an ethnic minority group was a significant predictor of death at a younger age. Specifically, the data suggest that being from a 'Mixed' ethnic background was associated with the highest risk (HR 3.19, 95% CI 2.86, 3.56), meaning that people denoted as 'Mixed' died at a younger age compared to the 'white' population. Whilst the HR's were smaller, each of the other three ethnic groups was also significantly associated with an earlier age at death in comparison to the 'white' group. The results of the Cox proportional hazard model are depicted in Figure 5, which displays the HR's and 95% confidence intervals. This is also displayed in Table 13.

**Figure 5.** A forest plot showing the associations between ethnicity and time to death (age) for deaths notified to LeDeR between 2018-2021. ‘White’ is the reference group.



**Table 13.** Summary of a Cox proportional hazard model to investigate the effect of ethnicity on age at death.

Level	Hazard Ratio	Standard Error	Lower 95% CI	Upper 95% CI
Mixed	3.19	.06	2.86	3.56
Black, Black British, Caribbean or African	2.84	.07	2.47	3.27
Asian or Asian British	2.35	.08	1.99	2.77
Other	1.26	.09	1.06	1.51

\* ‘White’ ethnicity is the reference group, with a hazard ratio of 1.

\* (N=11,138)

## Conclusion

The results of the survival analysis model suggest that ethnicity may be associated with age at death, with people from ethnic minorities dying at younger ages in comparison to those denoted as ‘white’. The risk of younger death was highest for people from a ‘Mixed’ ethnic background. These findings slightly differ from the 2021 LeDeR report, which found that being denoted as ‘Black, Black British, Caribbean or African’ was associated with the highest risk of a younger death, though the confidence intervals overlap.

## Section 5: LeDeR Data Analysis

The COVID-19 pandemic had a significant impact on the number of deaths and disproportionately affected certain at-risk groups (for example, those with existing conditions and from ethnic minorities), findings derived from combining pre and post pandemic data should be interpreted with caution. Furthermore, we did not consider other factors which are likely to influence age at death, such as demographic factors, indices of multiple deprivation and number of long-term health conditions.

Nonetheless, these findings corroborate previous research which suggests that people with learning disability from ethnic minorities die at a younger age than people from a white ethnic background with a learning disability. Future research is required regarding ethnicity and its association to premature deaths. This may require using datasets which contain larger sample sizes and more demographic variables.

It is likely that the deaths of people from ethnic minorities are under-reported to the LeDeR programme. We demonstrated that there was a greater proportion of deaths of people with a learning disability from a 'white' ethnic background reported to the LeDeR programme in 2021 than are in the general population. Furthermore, in the previous chapter about the analysis of ethnicity recording, we demonstrated that the demographic breakdown of patients on the learning disability register was comparable to the demographic breakdown of ethnicity when comparing to 2021 census data. Therefore, it is likely that the deaths of people from ethnic minorities are underreported to the LeDeR programme, rather than a greater proportion of deaths amongst people from a 'white' background.

Ethnicity was not a mandatory field in LeDeR notifications until 2021, so it could be that ethnicity information was not always available in notification data. However, the small numbers of ethnic minority groups in LeDeR data persisted in 2021 in comparison to the general population. Therefore, other factors may drive this underrepresentation of ethnic minorities.

Another possible explanation for an underrepresentation of people from ethnic minorities in LeDeR data is a lack of awareness of the programme. During our workshops with people with lived experience, both self-advocates and carers reported a lack of knowledge of the LeDeR programme. Targeted information about LeDeR to raise awareness of the value of the programme and its findings is essential for increasing engagement with LeDeR within communities. However, as most deaths reported to LeDeR are reported by professionals and not family members, lack of awareness in the community does not explain this underrepresentation.



## Recommendations

---

Actions for NHS England:

- Undertake a targeted awareness campaign amongst ethnic minority communities to help to tackle the under-reporting of deaths to the LeDeR programme.
- Medical Examiners in England should be provided with specific training and advice on identifying deaths of people with a learning disability and autistic people and notification to the LeDeR programme.

Actions for integrated care systems and boards:

- LeDeR reviewers should ensure that they accurately record in the LeDeR review the ethnicity of the person whose death they are reviewing. These data are best collected from the family as part of the review process, where the family can participate in the process.
- Ensure that the number of LeDeR reviews notified within their ICB reflect the demographics of their local population and take action to raise awareness of LeDeR within those communities, especially where notifications are below the anticipated number.

Actions for NIHR and other research bodies:

- Future research should further explore what is driving lower age at death in ethnic minorities with a learning disability, including avoidable causes of death and modifiable contributory factors.
- More detailed analysis is recommended for avoidable causes of death in ethnic minority populations and uptake of health promoting initiatives such as vaccination and screening programmes.

# Summary

This report highlights the importance of recognising racism as a driver of inequality in healthcare for people with a learning disability from ethnic minority backgrounds. These inequalities are reflected in a lack of consideration of people from ethnic minorities in policy, the poor quality and under-utilisation of ethnicity data in administrative datasets, and a paucity of research.

Variation in the completeness of ethnicity data in health and social care records, using valid ethnicity coding, limits the potential analysis and conclusions derived from data sources available. The accuracy of ethnicity recorded data are also hampered by variable methods for ascertaining ethnicity across health and social care settings, and we also know that people with a learning disability are more likely to have their ethnicity defined by a third party. Accuracy of ethnicity recording should be audited routinely, and further research should be considered as to how people with a learning disability can be supported to self-identify their ethnicity, such as using visual and audio methods to support written information.

A case study focus of a healthcare system, Lancashire and South Cumbria ICB, identified variability in the completeness of ethnicity recording across GP Practices but also the use of validated ethnicity codes. The extent to which this is the case across ICBs in England should be assessed. Moving towards consistent recording of ethnicity across different administrative datasets as well as adding data to datasets such as the Learning Disability Annual Health Check Scheme would further help to address inequalities. Lower numbers of notifications of deaths to the LeDeR Programme from ethnic minorities may reflect an underreporting of ethnic minorities given the higher prevalence of ethnic minority groups on the GP Learning Disability Registers in Lancashire and South Cumbria ICB. The reluctance and potential under recording of learning disability (particularly for those with mild learning disability) further clouds the accuracy of any analysis.

**Access:** The recent COVID-19 pandemic and pressures experienced across the health and social care systems, coupled with economic crisis, have made access to care challenging for the general population, but for people with a learning disability from ethnic minorities, disparities are likely to have been widened. The additional barriers faced by ethnic minorities requires implementation of ethnic specific reasonable adjustments. These should include measures such as facilitating care when needed at the first point of first contact with a health service provider particularly for those with a communication difficulty due to a language barrier for example.

## Summary

**Experience:** Overt racial discrimination was not an experience that was typically described by those with learning disability or carers. Recognition of systemic or subtle racial discrimination is either normalised as part of discrimination experienced because of disability, gender, age, or social inequality. Further work is needed to explore how people with a learning disability from ethnic minorities understand and conceptualise racism to further our understanding of how racism impacts their lives.

The sense of isolation and loneliness, for example, has been amplified during COVID-19 restriction for people with learning disability with additional impacts for ethnic minority groups whose social networks are limited. Development of culturally appropriate community-based support and self-advocacy groups supporting ethnic minority groups can address this.

**Outcomes:** Findings from the recent LeDeR data have confirmed the inequality in respect to mortality with ethnic minority populations with a learning disability dying up to 26 years younger than the 'white' group.

However, underlying predisposing risk factors such as gender, comorbidity and social factors are poorly understood and requires further research along with avoidable causes of death related to cancer, cardiovascular disease, epilepsy, and infections such as COVID, influenza and pneumonia.

There remains a significant gap in understanding the impact on care provided in relation to transition across health and social care settings and those moving from adolescent to adult care. The experience of certain minority community groups (Jewish and Roma for example) remains underrepresented in the research identified.

Specific consideration of those from an ethnic minority background with a learning disability is required across policy, administrative data recording systems and research to address the 'double discrimination' people may face as members of two marginalised groups.

# References

**Agardh, E., Allebeck, P., Hallqvist, J., Moradi, T., & Sidorchuk, A.** (2011). Type 2 diabetes incidence and socio-economic position: a systematic review and meta-analysis. *International Journal of Epidemiology*, 40(3), 804–818. <https://doi.org/10.1093/IJE/DYR029>

**Akbar, S., & Woods, K.** (2020). Understanding Pakistani parents' experience of having a child with special educational needs and disability (SEND) in England. *European Journal of Special Needs Education*, 35(5), 663–678.

**Ali, A., Scior, K., Ratti, V., Strydom, A., King, M., & Hassiotis, A.** (2013). Discrimination and other barriers to accessing health care: perspectives of patients with mild and moderate intellectual disability and their carers. *PloS One*, 8(8), e70855.

**Azmi, S., Hatton, C., ... E. E.-J.** of applied, & 1997, undefined. (1997). Listening to adolescents and adults with intellectual disabilities from South Asian communities. *Wiley Online Library*, 10(3), 250–263. <https://doi.org/10.1111/j.1468-3148.1997.tb00020.x>

**Baksh, R. A., Pape, S. E., Smith, J., & Strydom, A.** (2021). Understanding inequalities in COVID-19 outcomes following hospital admission for people with intellectual disability compared to the general population: a matched cohort study in the UK. *BMJ Open*, 11(10), e052482. <https://doi.org/10.1136/BMJOPEN-2021-052482>

**Beer, D., Turk, V., McGovern, P., Gravestock, S. M., Brooks, D., Barnett, L., & Orr, D.** (2005). Characteristics of patients exhibiting severe challenging behaviour in low secure mental health and mild learning disabilities units. *Journal of Psychiatric Intensive Care*, 1(1), 29–35.

**Bhardwaj, A. K., Forrester-Jones, R. V. E., & Murphy, G. H.** (2018). Social networks of adults with an intellectual disability from South Asian and White communities in the United Kingdom: A comparison. *Journal of Applied Research in Intellectual Disabilities*, 31(2), e253–e264.

**Bhaumik, S., Tyrer, F. C., McGrother, C., & Ganghadaran, S. K.** (2008). Psychiatric service use and psychiatric disorders in adults with intellectual disability. *Journal of Intellectual Disability Research*, 52(11), 986–995.

**Bhaumik, S., Watson, J., Barrett, M., Raju, B., Burton, T., & Forte, J.** (2011). Transition for teenagers with intellectual disability: Carers' perspectives. *Journal of Policy and Practice in Intellectual Disabilities*, 8(1), 53–61.

**Bisquera, A., Turner, E. B., Ledwaba-Chapman, L., Dunbar-Rees, R., Hafezparast, N., Gulliford, M., ... & Wang, Y.** (2022). Inequalities in developing multimorbidity over time: a population-based cohort study from an urban, multi-ethnic borough in the United Kingdom. *The Lancet Regional Health-Europe*, 12, 100247.

**Bone, A., Mc Grath-Lone, L., Day, S., & Ward, H.** (2014). Inequalities in the care experiences of patients with cancer: analysis of data from the National Cancer Patient Experience Survey 2011–2012. *BMJ Open*, 4(2), e004567.

**Bonell, S., Ali, A., Hall, I., Chinn, D., & Patkas, I.** (2011). People with intellectual disabilities in out-of-area specialist hospitals: what do families think? *Journal of Applied Research in Intellectual Disabilities*, 24(5), 389–397.

**Bonell, S., Underwood, L., Radhakrishnan, V., & McCarthy, J.** (2012). Experiences of mental health services by people with intellectual disabilities from different ethnic groups: a Delphi consultation. *Journal of Intellectual Disability Research*, 56(9), 902–909.

**Bouras, N., Cowley, A., Holt, G., Newton, J. T., & Sturmey, P.** (2003). Referral trends of people with intellectual disabilities and psychiatric disorders. *Journal of Intellectual Disability Research*, 47(6), 439–446.

## References

- Bower, P., Grigoroglou, C., Anselmi, L., Kontopantelis, E., Sutton, M., Ashworth, M., Evans, P., Lock, S., Smye, S., & Abel, K.** (2020). Is health research undertaken where the burden of disease is greatest? Observational study of geographical inequalities in recruitment to research in England 2013-2018. *BMC Medicine*, 18(1), 1–11. <https://doi.org/10.1186/S12916-020-01555-4/TABLES/3>
- Burke, C.-K., & Ong, L.** (n.d.). *Collaboratives on addressing racial inequity in covid recovery Learning Disability Briefing Paper*.
- Care for people with a learning disability during the pandemic - Care Quality Commission.* (n.d.). Retrieved February 7, 2023, from <https://www.cqc.org.uk/news/stories/care-people-learning-disability-during-pandemic>
- Carey, I. M., Cook, D. G., Harris, T., DeWilde, S., Chaudhry, U. A. R., & Strachan, D. P.** (2021). Risk factors for excess all-cause mortality during the first wave of the COVID-19 pandemic in England: A retrospective cohort study of primary care data. *Plos One*, 16(12), e0260381.
- Caton, S., Starling, S., Burton, M., Azmi, S., & Chapman, M.** (2007). Responsive services for people with learning disabilities from minority ethnic communities. *British Journal of Learning Disabilities*, 35(4), 229.
- Chadwick, O., Kusel, Y., Cuddy, M., & Taylor, E.** (2005). Psychiatric diagnoses and behaviour problems from childhood to early adolescence in young people with severe intellectual disabilities. *Psychological Medicine*, 35(5), 751–760.
- Chaplin, E., McCarthy, J., Underwood, L., Forrester, A., Hayward, H., Sabet, J., Mills, R., Young, S., Asherson, P., & Murphy, D.** (2017). Characteristics of prisoners with intellectual disabilities. *Journal of Intellectual Disability Research*, 61(12), 1185–1195.
- Chaplin, R. H., Thorp, C., Ismail, I. A., Collacott, R. A., & Bhaumik, S.** (1996). Psychiatric disorder in Asian adults with learning disabilities: patterns of service use. *Journal of Intellectual Disability Research*, 40(4), 298–304.
- Chen, S., She, R., Qin, P., Kershenbaum, A., Fernandez-Egea, E., Nelder, J. R., Ma, C., Lewis, J., Wang, C., & Cardinal, R. N.** (2020). The medium-term impact of COVID-19 lockdown on referrals to secondary care mental health services: a controlled interrupted time series study. *Frontiers in Psychiatry*, 11, 585915.
- Chinn, D., Hall, I., Ali, A., Hassell, H., & Patkas, I.** (2011). Psychiatric in-patients away from home: accounts by people with intellectual disabilities in specialist hospitals outside their home localities. *Journal of Applied Research in Intellectual Disabilities*, 24(1), 50–60.
- Chitsabesan, P., Kroll, L., Bailey, S. U. E., Kenning, C., Sneider, S., MacDonald, W., & Theodosiou, L.** (2006). Mental health needs of young offenders in custody and in the community. *The British Journal of Psychiatry*, 188(6), 534–540.
- Craig, G. M., & Scambler, G.** (2006). Negotiating mothering against the odds: Gastrostomy tube feeding, stigma, governmentality and disabled children. *Social Science & Medicine*, 62(5), 1115–1125.
- Croot, E., Grant, G., Mathers, N., & Cooper, C.** (2012). Coping strategies used by Pakistani parents living in the United Kingdom and caring for a severely disabled child. *Disability and Rehabilitation*, 34(18), 1540–1549.
- Croot, E. J.** (2012). The care needs of Pakistani families caring for disabled children: how relevant is cultural competence? *Physiotherapy*, 98(4), 351–356.
- Cummins, L., Ebyarimpa, I., Cheetham, N., Tzortziou Brown, V., Brennan, K., & Panovska-Griffiths, J.** (2021). Factors associated with COVID-19 related hospitalisation, critical care admission and mortality using linked primary and secondary care data. *Influenza and Other Respiratory Viruses*, 15(5), 577–588.
- Curtis, H. J., Inglesby, P., Morton, C. E., MacKenna, B., Green, A., Hulme, W., Walker, A. J., Morley, J., Mehrkar, A., & Bacon, S.** (2022). Trends and clinical characteristics of COVID-19 vaccine recipients: a federated analysis of 57.9 million patients' primary care records in situ using OpenSAFELY. *British Journal of General Practice*, 72(714), e51–e62.

## References

- Das-Munshi, J., Chang, C. K., Bakolis, I., Broadbent, M., Dregan, A., Hotopf, M., Morgan, C., & Stewart, R.** (2021). All-cause and cause-specific mortality in people with mental disorders and intellectual disabilities, before and during the COVID-19 pandemic: cohort study. *The Lancet Regional Health-Europe*, 11, 100228.
- Davis, H., & Rushton, R.** (1991). Counselling and supporting parents of children with developmental delay: a research evaluation. *Journal of Intellectual Disability Research*, 35(2), 89–112.
- Devapriam, J., Thorp, C., Tyrer, F., Gangadharan, S., Raju, L., & Bhaumik, S.** (2008). A comparative study of stress and unmet needs in carers of South Asian and white adults with learning disabilities. *Ethnicity and Inequalities in Health and Social Care*, 1(2), 35–43.
- Dobson, S., & Upadhyaya, S.** (2002). Concepts of autism in Asian communities in Bradford, UK. *Good Autism Practice*, 3(2), 43–51.
- Donetto, S., Pierri, P., Tsianakas, V., & Robert, G.** (2015). Experience-based Co-design and Healthcare Improvement: Realizing Participatory Design in the Public Sector. <http://dx.doi.org/10.2752/175630615X14212498964312>, 18(2), 227–248. <https://doi.org/10.2752/175630615X14212498964312>
- Doshi, M., Burke, M., & Fiske, J.** (2009). A preliminary investigation into aspects of oral health of Bangladeshi young adults with learning disability in Tower Hamlets. *J Disabil Oral Health*, 10, 25–35.
- Dunkley, A. J., Tyrer, F., Gray, L. J., Bhaumik, S., Spong, R., Chudasama, Y., Cooper, S., Ganghadaran, S., Davies, M., & Khunti, K.** (2017). Type 2 diabetes and glucose intolerance in a population with intellectual disabilities: the STOP diabetes cross-sectional screening study. *Journal of Intellectual Disability Research*, 61(7), 668–681.
- Durà-Vilà, G., & Hodes, M.** (2009). Ethnic variation in service utilisation among children with intellectual disability. *Journal of Intellectual Disability Research*, 53(11), 939–948.
- Durling, E., Chinn, D., & Scior, K.** (2018). Family and community in the lives of UK Bangladeshi parents with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 31(6), 1133–1143.
- Ellis, J., Logan, S., Pumphrey, R., Tan, H. K., Henley, W., Edwards, V., Moy, R., & Gilbert, R.** (2008). Inequalities in provision of the Disability Living Allowance for Down syndrome. *Archives of Disease in Childhood*, 93(1), 14–16.
- Emerson, E.** (2012). Deprivation, ethnicity and the prevalence of intellectual and developmental disabilities. *J Epidemiol Community Health*, 66(3), 218–224.
- Emerson, E., Azmi, S., Hatton, C., Caine, A., Parrott, R., & Wolstenholme, J.** (1997). Is there an increased prevalence of severe learning disabilities among British Asians? *Ethnicity & Health*, 2(4), 317–321.
- Emerson, E., Robertson, J., & Wood, J.** (2004). Levels of psychological distress experienced by family carers of children and adolescents with intellectual disabilities in an urban conurbation. *Journal of Applied Research in Intellectual Disabilities*, 17(2), 77–84.
- Emerson, E., Robertson, J., & Wood, J.** (2005). Emotional and behavioural needs of children and adolescents with intellectual disabilities in an urban conurbation. *Journal of Intellectual Disability Research*, 49(1), 16–24.
- Emerson, E., Robertson, J., & Wood, J.** (2007). The association between area-level indicators of social deprivation and the emotional and behavioural needs of black and South Asian children with intellectual disabilities in a deprived urban environment. *Journal of Applied Research in Intellectual Disabilities*, 20(5), 420–429.
- Equality Act 2010: guidance* - GOV.UK. (n.d.). Retrieved February 7, 2023, from <https://www.gov.uk/guidance/equality-act-2010-guidance>
- Estimates of the population for the UK, England, Wales, Scotland and Northern Ireland* - Office for National Statistics. (n.d.). Retrieved February 6, 2023, from <https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/populationestimatesforukenglandandwalesscotlandandnorthernireland>



## References

- Ethnicity - NHS Digital*. (n.d.). Retrieved February 6, 2023, from <https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-sets/mental-health-services-data-set/submit-data/data-quality-of-protected-characteristics-and-other-vulnerable-groups/ethnicity>
- Harmonised Concepts and Questions for Social Data Sources Primary Principles Ethnic Group. (2015). <https://gss.civilservice.gov.uk/wp-content/uploads/2016/03/S11-National-Identity-and-Religion-June-16.pdf>
- Hatton, C., Azmi, S., Caine, A., & Emerson, E.** (1998). Informal carers of adolescents and adults with learning difficulties from the South Asian communities: family circumstances, service support and carer stress. *The British Journal of Social Work*, 28(6), 821–837.
- Hatton, C., Bailey, T., Bradshaw, J., Caton, S., Flynn, S., Gillooly, A., Jahoda, A., Maguire, R., Marriott, A., & Mulhall, P.** (2021). The willingness of UK adults with intellectual disabilities to take COVID-19 vaccines. *Journal of Intellectual Disability Research*, 65(11), 949–961.
- Hatton, C., & Emerson, E.** (2009). Does socioeconomic position moderate the impact of child behaviour problems on maternal health in South Asian families with a child with intellectual disabilities? *Journal of Intellectual and Developmental Disability*, 34(1), 10–16.
- Hatton, C., Emerson, E., Kirby, S., Kotwal, H., Baines, S., Hutchinson, C., Dobson, C., & Marks, B.** (2010). Majority and minority ethnic family carers of adults with intellectual disabilities: perceptions of challenging behaviour and family impact. *Journal of Applied Research in Intellectual Disabilities*, 23(1), 63–74.
- Heer, K., Larkin, M., & Rose, J.** (2015). The experiences of British South Asian carers caring for a child with developmental disabilities in the UK. *Tizard Learning Disability Review*, 20(4), 228–238.
- Heer, K., Rose, J., & Larkin, M.** (2014). The Challenges of Providing Culturally Competent Care Within a Disability Focused Team. <http://Dx.Doi.Org/10.1177/1043659614526454>, 27(2), 109–116. <https://doi.org/10.1177/1043659614526454>
- Hersov, E. K.** (2007). What does being Jewish mean to you? The spiritual needs of Jewish people with learning disabilities and their families. *Journal of Religion, Disability & Health*, 10(3–4), 183–205.
- Hoghton, M., Martin, G., & Chauhan, U.** (2012). Annual health checks for people with intellectual disabilities. In Bmj (Vol. 345). *British Medical Journal Publishing Group*.
- Hubert, J.** (2006). Family carers' views of services for people with learning disabilities from Black and minority ethnic groups: a qualitative study of 30 families in a south London borough. *Disability & Society*, 21(3), 259–272.
- Johnson, S., Evans, T. A., Draper, E. S., Field, D. J., Manktelow, B. N., Marlow, N., Matthews, R., Petrou, S., Seaton, S. E., & Smith, L. K.** (2015). Neurodevelopmental outcomes following late and moderate prematurity: a population-based cohort study. *Archives of Disease in Childhood-Fetal and Neonatal Edition*, 100(4), F301–F308.
- Johnson-Lawrence, V., Zajacova, A., & Sneed, R.** (2017). Education, race/ethnicity, and multimorbidity among adults aged 30-64 in the National Health Interview Survey. *SSM - Population Health*, 3, 366–372. <https://doi.org/10.1016/J.SSMPH.2017.03.007>
- Joy, M., Hobbs, F. D. R., Bernal, J. L., Sherlock, J., Amirthalingam, G., McGagh, D., Akinyemi, O., Byford, R., Dabrera, G., & Dorward, J.** (2020). Excess mortality in the first COVID pandemic peak: cross-sectional analyses of the impact of age, sex, ethnicity, household size, and long-term conditions in people of known SARS-CoV-2 status in England. *British Journal of General Practice*, 70(701), e890–e898.
- Kapadia, D., & Bradby, H.** (2021). Ethnicity and health. *Routledge International Handbook of Critical Issues in Health and Illness*, 183–196. <https://doi.org/10.4324/9781003185215-17>
- Kerr, G. R. D.** (2001). Assessing the needs of learning disabled young people with additional disabilities: Implications for planning adult services. *Journal of Learning Disabilities*, 5(2), 157–174.

## References

- Kiani, R., Tyrer, F., Hodgson, A., Berkin, N., & Bhaumik, S.** (2013). Urban–rural differences in the nature and prevalence of mental ill-health in adults with intellectual disabilities. *Journal of Intellectual Disability Research*, 57(2), 119–127.
- Kramer-Roy, D.** (2012). Supporting ethnic minority families with disabled children: learning from Pakistani families. *British Journal of Occupational Therapy*, 75(10), 442–448.
- Kroll, L., Rothwell, J., Bradley, D., Shah, P., Bailey, S., & Harrington, R. C.** (2002). Mental health needs of boys in secure care for serious or persistent offending: a prospective, longitudinal study. *The Lancet*, 359(9322), 1975–1979.
- Larkin, M., Unwin, G., Iyer, M., Tsimopoulou, I., Zahid, S., Malik, K., Stenfert Kroese, B., & Rose, J. L.** (2018). Cultural affordance, social relationships, and narratives of independence: Understanding the meaning of social care for adults with intellectual disabilities from minority ethnic groups in the UK. *International Journal of Developmental Disabilities*, 64(3), 195–203.
- Learning from Lives and Deaths - people with a learning disability and autistic people (LeDeR)*. (n.d.). Retrieved February 7, 2023, from <https://www.kcl.ac.uk/research/leder>
- LeDeR - Annual reports*. (n.d.). Retrieved February 7, 2023, from <https://leder.nhs.uk/resources/annual-reports>
- Leese, M., Thornicroft, G., Shaw, J., Thomas, S., Mohan, R., Harty, M. A., & Dolan, M.** (2006). Ethnic differences among patients in high-security psychiatric hospitals in England. *The British Journal of Psychiatry*, 188(4), 380–385.
- L'Esperance, V., Schofield, P., & Ashworth, M.** (2021). The provision of additional services in primary care: a cross-sectional study of incentivised additional services, social deprivation, and ethnic group. *BJGP Open*, 5(1).
- Linehan, S. A., Duffy, D. M., O'Neill, H., O'Neill, C., & Kennedy, H. G.** (2002). Irish Travellers and forensic mental health. *Irish Journal of Psychological Medicine*, 19(3), 76–79.
- Liverpool, S., Hayes, D., & Edbrooke-Childs, J.** (2021). Parent/Carer-reported experience of shared decision making at child and adolescent mental health services: A multilevel modelling approach. *Frontiers in Psychiatry*, 12, 676721.
- Maitland, C. H., Tsakanikos, E., Holt, G., & Bouras, N.** (2006). Mental health service provision for adults with intellectual disability: sources of referrals, clinical characteristics and pathways to care. *Primary Care Mental Health*, 4(2), 99.
- Malik, K. J., Unwin, G., Larkin, M., Kroese, B. S., & Rose, J.** (2017). The complex role of social care services in supporting the development of sustainable identities: Insights from the experiences of British South Asian women with intellectual disabilities. *Research in Developmental Disabilities*, 63, 74–84.
- Marr, J. E., Halliwell-Ewen, J., Fisher, B., Soler, L., & Ainsworth, J. R.** (2001). Associations of high myopia in childhood. *Eye*, 15(1), 70–74.
- Masefield, S. C., Prady, S. L., Sheldon, T. A., Small, N., Jarvis, S., & Pickett, K. E.** (2022). The effects of caring for young children with developmental disabilities on mothers' health and healthcare use: analysis of primary care data in the Born in Bradford Cohort. *Journal of Developmental and Physical Disabilities*, 34(1), 67–87.
- Mathur, R., Bhaskaran, K., Chaturvedi, N., Leon, D. A., van Staa, T., Grundy, E., & Smeeth, L.** (2014). Completeness and usability of ethnicity data in UK-based primary care and hospital databases. *Journal of Public Health (Oxford, England)*, 36(4), 684–692. <https://doi.org/10.1093/PUBMED/FDT116>
- McCarthy, M., Clawson, R., Patterson, A., Fyson, R., & Khan, L.** (2021). Risk of forced marriage amongst people with learning disabilities in the UK: Perspectives of South Asian carers. *Journal of Applied Research in Intellectual Disabilities*, 34(1), 200–210.
- McClimens, A., Lewis, R., & Brewster, J.** (2013). Dr. Tulp, I presume: Intellectual disability and ethnicity in Rotherham. *Journal of Intellectual Disabilities*, 17(1), 78–89.



## References

- McGrother, C. W., Bhaumik, S., Thorp, C. F., Watson, J. M., & Taub, N. A.** (2002). Prevalence, morbidity and service need among South Asian and white adults with intellectual disability in Leicestershire, UK. *Journal of Intellectual Disability Research*, 46(4), 299–309.
- Morris, D. J., Webb, E. L., Foster-Davies, L., Wallang, P. M., Gibbs, D., McAllister, P. D., & Shaddel, F.** (2021). Ethnic disparity in mental health legislation at the point of inpatient entry: pilot review in detained adolescents with developmental disorders. *The Journal of Forensic Practice*, 23(3), 240–253.
- Morton, R., Sharma, V., Nicholson, J., Broderick, M., & Poyser, J.** (2002). Disability in children from different ethnic populations. *Child: Care, Health and Development*, 28(1), 87–93.
- Munroe, K., Hammond, L., & Cole, S.** (2016). The experiences of African immigrant mothers living in the United Kingdom with a child diagnosed with an autism spectrum disorder: an interpretive phenomenological analysis. *Disability & Society*, 31(6), 798–819.
- NHS England.** (n.d.). *Increasing diversity in research participation: A good practice guide for engaging with underrepresented groups*.
- NHS Race and Health Observatory** (2022) (n.d.). *NHS Race & Health Observatory Terminology Consultation Report - NHS - Race and Health Observatory*. Retrieved February 7, 2023, from <https://www.nhs.uk/publications/nhs-race-health-observatory-terminology-consultation-report/>
- O'Hara, J., & Martin, H.** (2003). Parents with learning disabilities: a study of gender and cultural perspectives in East London. *British Journal of Learning Disabilities*, 31(1), 18–24.
- Office for National Statistics** (2023). *Why have Black and South Asian people been hit hardest by COVID-19? - Office for National Statistics*. (n.d.). Retrieved February 6, 2023, from <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/articles/whyhaveblackandsouthasianpeoplebeenhithardestbycovid19/2020-12-14>
- Parrott, R., Tilley, N., & Wolstenholme, J.** (2008). Changes in demography and demand for services from people with complex needs and profound and multiple learning disabilities. *Tizard Learning Disability Review*.
- Parry, B. J., Quinton, M. L., Holland, M. J. G., Thompson, J. L., & Cumming, J.** (2021). Improving outcomes in young people experiencing homelessness with My Strengths Training for Life™(MST4Life™): A qualitative realist evaluation. *Children and Youth Services Review*, 121, 105793.
- Raghavan, R., Newell, R., Waseem, F., & Small, N.** (2009). A randomized controlled trial of a specialist liaison worker model for young people with intellectual disabilities with challenging behaviour and mental health needs. *Journal of Applied Research in Intellectual Disabilities*, 22(3), 256–263.
- Raghavan, R., & Waseem, F.** (2007). Services for young people with learning disabilities and mental health needs from South Asian communities. *Advances in Mental Health and Learning Disabilities*, 1(3), 27–31.
- Robertson, J., Raghavan, R., Emerson, E., Baines, S., & Hatton, C.** (2019). What do we know about the health and health care of people with intellectual disabilities from minority ethnic groups in the United Kingdom? A systematic review. *Journal of Applied Research in Intellectual Disabilities*, 32(6), 1310–1334. <https://doi.org/10.1111/JAR.12630>
- Ruane, A., Carr, A., Moffat, V., Finn, T., Murphy, A., O'Brien, O., Groarke, H., & O'Dwyer, R.** (2019). A randomised controlled trial of the Group Stepping Stones Triple P training programme for parents of children with developmental disabilities. *Clinical Child Psychology and Psychiatry*, 24(4), 728–753.
- Russ, S., Sevdalis, N., & Ocloo, J.** (2021). A smartphone app designed to empower patients to contribute toward safer surgical care: qualitative evaluation of diverse public and patient perceptions using focus groups. *JMIR MHealth and UHealth*, 9(4), e24065.
- SAGE meetings, July 2020 - GOV.UK.* (n.d.). Retrieved February 7, 2023, from <https://www.gov.uk/government/collections/sage-meetings-july-2020>
- Sandhu, P., Ibrahim, J., & Chinn, D.** (2017). 'I Wanted to Come Here Because of My Child': Stories of Migration Told by Turkish-Speaking Families Who Have a Son or Daughter with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities*, 30(2), 371–382.

## References

- Scobie, S., Spencer, J., Trust, V. R.-N., & 2021, undefined.** (2021). Ethnicity coding in English health service datasets. *Allcatsrgrey.Org.Uk*. [http://allcatsrgrey.org.uk/wp/download/public\\_health/epidemiology/1622731816\\_nuffield-trust-ethnicity-coding-web.pdf](http://allcatsrgrey.org.uk/wp/download/public_health/epidemiology/1622731816_nuffield-trust-ethnicity-coding-web.pdf)
- Sham, S.** (1996). Reaching Chinese children with learning disabilities in greater Manchester. *British Journal of Learning Disabilities*, 24(3), 104–109.
- Stafford, M., Knight, H., Hughes, J., Alarilla, A., Mondor, L., Pefoyo Kone, A., ... & Deeny, S. R.** (2022). Associations between multiple long-term conditions and mortality in diverse ethnic groups. *Plos one*, 17(4), e0266418.
- Sturmey, P.** (2009). Restraint, seclusion and PRN medication in English services for people with learning disabilities administered by the National Health Service: An analysis of the 2007 National Audit Survey. *Journal of Applied Research in Intellectual Disabilities*, 22(2), 140–144.
- Terashima, S.** (2011). Personalisation of care for people from South Asian communities. *Learning Disability Practice*, 14(2).
- Tsakanikos, E., McCarthy, J., Kravariti, E., Fearon, P., & Bouras, N.** (2010). The role of ethnicity in clinical psychopathology and care pathways of adults with intellectual disabilities. *Research in Developmental Disabilities*, 31(2), 410–415.
- Tuffrey-Wijne, I., & Rose, T.** (2017). Investigating the factors that affect the communication of death-related bad news to people with intellectual disabilities by staff in residential and supported living services: An interview study. *Journal of Intellectual Disability Research*, 61(8), 727–736.
- Tyrer, F., Dunkley, A. J., Singh, J., Kristunas, C., Khunti, K., Bhaumik, S., Davies, M. J., Yates, T. E., & Gray, L. J.** (2019). Multimorbidity and lifestyle factors among adults with intellectual disabilities: a cross-sectional analysis of a UK cohort. *Journal of Intellectual Disability Research*, 63(3), 255–265.
- Tyrer, F., Ling, S., Bhaumik, S., Gangadharan, S. K., Khunti, K., Gray, L. J., & Dunkley, A. J.** (2020a). Diabetes in adults with intellectual disability: prevalence and associated demographic, lifestyle, independence and health factors. *Journal of Intellectual Disability Research*, 64(4), 287–295.
- Tyrer, F., McGrother, C. W., Thorp, C. F., Donaldson, M., Bhaumik, S., Watson, J. M., & Hollin, C.** (2006). Physical aggression towards others in adults with learning disabilities: prevalence and associated factors. *Journal of Intellectual Disability Research*, 50(4), 295–304.
- Tyrer, F., Smith, L. K., McGrother, C. W., & Taub, N. A.** (2007). The impact of physical, intellectual and social impairments on survival in adults with intellectual disability: A population-based register study. *Journal of Applied Research in Intellectual Disabilities*, 20(4), 360–367.
- Understanding consistency of ethnicity data recorded in health-related administrative datasets in England - Office for National Statistics.* (n.d.). Retrieved February 7, 2023, from <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthinequalities/articles/understandingconsistencyofethnicitydatarecordedinhealthrelatedadministrativedatasetsinengland2011to2021/2023-01-16>
- Verity, C., Baker, E., Maunder, P., Pal, S., & Winstone, A. M.** (2021a). Differential diagnosis of progressive intellectual and neurological deterioration in children. *Developmental Medicine & Child Neurology*, 63(3), 287–294.
- Winstone, A. M., Stellitano, L. A., & Verity, C. M.** (2017). Niemann–Pick type C as a cause of progressive intellectual and neurological deterioration in childhood. *Developmental Medicine & Child Neurology*, 59(9), 965–972.
- White, A; Sheehan, R; Ding, J; Roberts, C; Magill, N; Keagan-Bull, R; Carter, B; Ruane, M; Xiang, X; Chauhan, U; Tuffrey-Wijne, I; Strydom, A;** (2022). Learning from Lives and Deaths - People with a learning disability and autistic people (LeDeR) report for 2021 (LeDeR 2021). Autism and learning disability partnership, King's College, London
- Wood, N. S., Costeloe, K., Gibson, A. T., Hennessy, E. M., Marlow, N., & Wilkinson, A. R.** (2005). The EPICure study: associations and antecedents of neurological and developmental disability at 30 months of age following extremely preterm birth. *Archives of Disease in Childhood-Fetal and Neonatal Edition*, 90(2), F134–F140.



[nhsrho.org](https://nhsrho.org)



[@nhs\\_rho](https://twitter.com/nhs_rho)