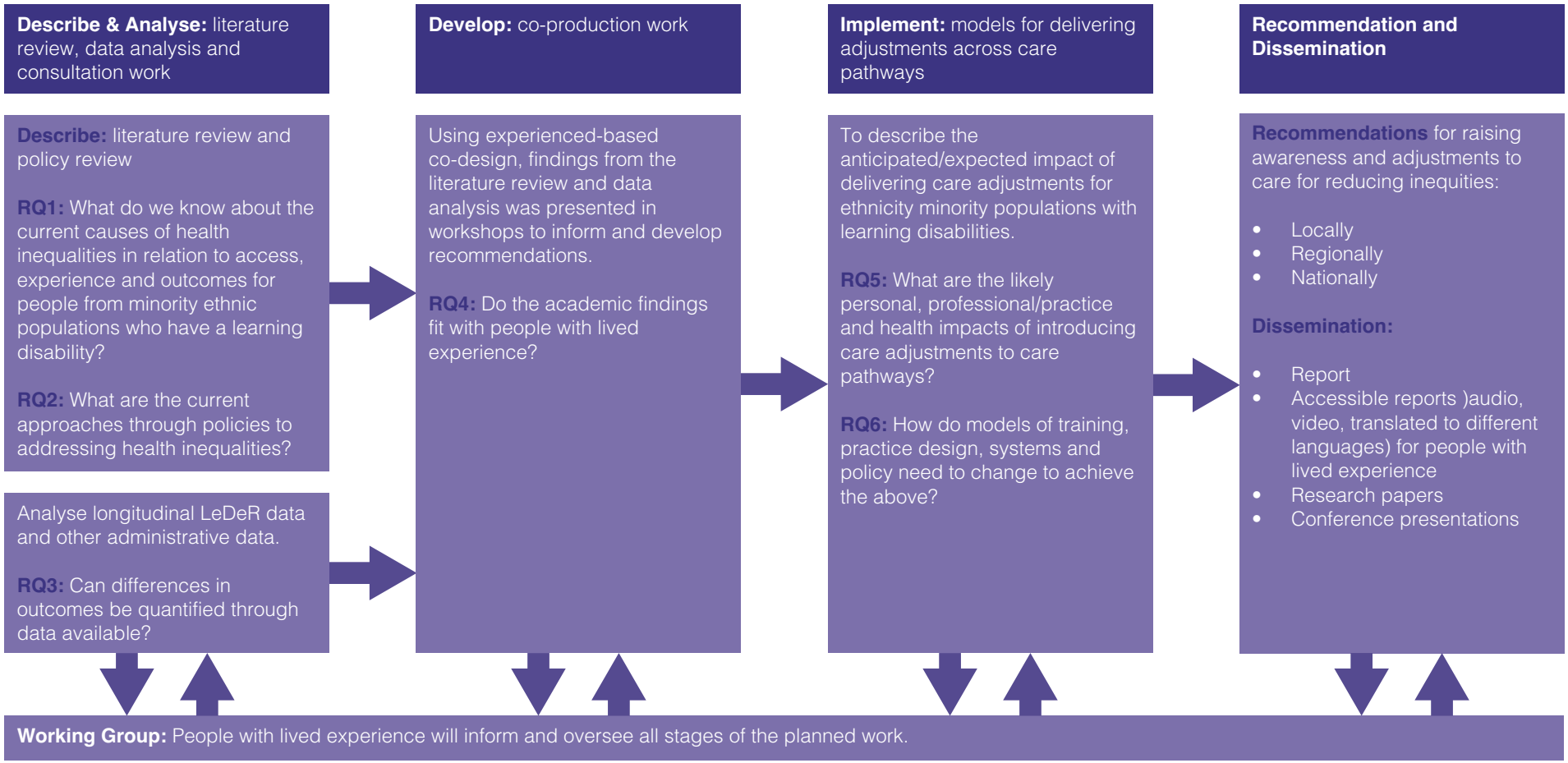
NHS RACE & HEALTH OBSERVATORY

Appendices

Appendix 0

Figure 1: Study flow diagram: Addressing health inequalities for people with a learning disability from ethnic minority backgrounds



Appendix 1: Policy Review

The following tables show all the documents searched in the process of this review, which took place in May - June 2022, with an update in September 2022:

- Table a: Legislation
- Table b: National policy (England)
- Table c: National policies focusing on people with learning disabilities (other parts of the UK)

Table A: Legislation

Author	Year	Publication	Information in relation to people with Learning Disabilities from Black and minoritised communities
HM Government	2000	Carers and Disabled Children Act 2000 (Repealed) https://www.legislation.gov.uk/ukpga/2000/16/contents	No information in relation to people with learning disabilities from Black and minoritised communities.
HM Government	2014	Children and Families Act 2014 https://www.legislation.gov.uk/ukpga/2014/6/contents/enacted	No information in relation to people with learning disabilities from Black and minoritised communities.
HM Government	2014	Care Act 2014 https://www.legislation.gov.uk/ukpga/2014/23/contents/enacted	No information in relation to people with learning disabilities from Black and minoritised communities.
HM Government	2022	Down Syndrome Act 2022 https://www.legislation.gov.uk/ukpga/2022/18/enacted	No information in relation to people with learning disabilities from Black and minoritised communities.

Table B: Government / NHS / arms length bodies policies and responses

Author	Year	Publication	Information in relation to people with Learning Disabilities from Black and minoritised communities
Department of Health [DH]	2001	Valuing People - A New Strategy for Learning Disability for the 21st Century https://www.gov.uk/government/publications/valuing-people-a-new-strategy-for-learning-disability-for-the-21st-century	The needs of people from minority ethnic communities are often overlooked; Councils will be encouraged to identify carers aged over 70 and those from minority ethnic communities, ensuring that carers and their organisations are represented on the Learning Disability Task Force. Ensure that people with learning disabilities, including those from minority ethnic communities, have the same right of access to mainstream health services as the rest of the population. The NHS will promote equality for people with learning disabilities from minority ethnic communities in accordance with the Race Relations (Amendment) Act 2000. Evidence suggests that the number of people with severe learning disabilities may increase by around 1% per annum for the next 15 years as a result of several factors including greater prevalence among some minority ethnic populations of South Asian origin. The needs of people with learning disabilities from minority ethnic communities are too often overlooked. Key findings from the study by the Centre for Research in Primary Care at the University of Leeds published alongside Valuing People included: • Prevalence of learning disability in some South Asian communities can be up to three times greater than in the general population; • Diagnosis is often made at a later age than for the population as a whole and parents receive less information about their child's condition and the support available; • Social exclusion is made more severe by language barriers and racism, and negative stereotypes and attitudes contribute to disadvantage;

			• Carers who do not speak English receive less information about their support role and experience high levels of stress; and • Agencies often underestimate people's attachments to cultural traditions and religious beliefs. The report also makes reference to challenges- socioeconomic, social exclusion, poverty, reduced life opportunities, noting that those from minority ethnic families experience these barriers disproportionately. People with learning disabilities from minority ethnic communities can find it particularly difficult to gain access to the advocacy support they need. The Government will ensure that our new initiatives are responsive to their needs. The Department of Health will issue good practice materials to help with this. The Carers Grant: Meeting the Needs of Older Carers and Carers from Minority Ethnic Communities 5.10 Family Matters, Counting Families In published alongside Valuing People identifies three groups of carers who face additional pressures: older carers (those aged 70 or over), carers from minority ethnic communities and carers whose sons or daughters are going through transition from school to adult life. Chapter 3 looks at transition, and we discuss below the other two priority groups. Both face additional difficulties in carrying out their caring role effectively. 5.12 Difficulties facing carers from minority ethnic communities include insensitivity to issues of culture and language and false assumptions about communities wishing to provide care within their own family environment or putting up barriers against statutory agencies. All services for carers should be responsive to the needs of people from minority ethnic communities.

			6.10 People with learning disabilities from minority ethnic communities are at particular risk of discrimination in gaining access to appropriate health care. Problems arise if professionals are not aware of cultural or language issues or only use English language based.
Department of Health [DH]	2007	Services for people with learning disability and challenging behaviour or mental health needs (Mansell report) https://research.kent.ac.uk/tizard/wp-content/uploads/sites/2302/2019/01/dh2007mansellreport.pdf	In considering individual need, the same attention to issues of race and gender as required in other services should apply. There is evidence from mental health services of different, more restrictive, treatment of service users from ethnic minorities. Services will ensure that each person is treated as a full and valued member of their community, with the same rights as everyone else and with respect for their culture, ethnic origin and religion.
HM Government	2007	Putting People First: A shared vision and commitment to the transformation of Adult Social Care https://www.basw.co.uk/system/files/resources/basw_102631-4_0.pdf	No information in relation to people with learning disabilities from Black and minoritised communities.
HM Treasury/ Department for Education and Skills	2007	Aiming High for Disabled Children: Better Support for Families (2007) https://www.pmguk.co.uk/data/page_files/publications%20and%20reports/2007/R.AiminghighforDisabledChilden.pdf	Sought to present solutions to the particular problems faced by groups of autistic children, children with complex health needs and children from black and minority ethnic communities. No information in relation to people with learning disabilities from Black and minoritised communities.

Department for Children, Schools, and Families	2007	The Children's Plan: building brighter futures. DCsF CM7280 (2007). https://www.gov.uk/government/publications/the-childrens-plan	No information in relation to people with learning disabilities from Black and minoritised communities. Highlights concerns about the extent to which permanent exclusion continues to bear disproportionately on certain groups of children and young people, such as Black Caribbean children. Acknowledges that particular groups, such as disabled children and those from black and minority ethnic groups, are especially likely to live in poverty. Some black and minority ethnic groups are disproportionately more likely to be disadvantaged and on average achieve lower results at school. Black Caribbean, Black African and other Black pupils, those of Mixed White and Black Caribbean heritage, Bangladeshi and Pakistani pupils perform below the national average at all Key Stages.
Department of Health [DH]	2008	Healthcare for All, Report of the independent inquiry into Access to Healthcare for People with Learning Disabilities, Sir Jonathan Michael http://docplayer.net/70078-Healthcare-for-all-report-of-the-independent-inquiry-into-access-to-healthcare-for-people-with-learning-disabilities-sir-jonathan-michael.html	The prevalence of learning disability in the general population is expected to rise by around one per cent per annum for the next 10 years and to grow overall by over ten per cent by 2020. In addition, there are increases anticipated in the proportion of younger English adults from South Asian minority ethnic communities, where the prevalence of learning disability is higher. The report goes on to refer to the evidence base, acknowledging that those with learning disabilities from a minority ethnic group have greater mortality, but fail to make recommendations specific to this population group.
Department of Health [DH]	2008	Carers at the heart of 21st-century families and communities https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/136492/carers_at_the_heart_of_21_century_families.pdf	Does not explicitly make reference to carers of people with learning disabilities from Black and minoritised communities. However, it highlights the need for tailored support and training for carers from Black and minoritised backgrounds. The public consultation scheme sought the views of carers from a wide variety of groups, including Black and minoritised groups, parent and young carers. They found that Bangladeshi and Pakistani groups are more likely to be carers than any other ethnic group.

Department for Work and Pensions (DWP)	2008	Green Paper No one written off: reforming welfare to reward responsibility, Department for Work and Pensions (2008); White Paper Raising expectations and increasing support: reforming welfare for the future. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/238741/7363.pdf	Does not explicitly make reference to carers of people with learning disabilities from Black and minoritised communities. However, acknowledges that people from ethnic minorities live in the most deprived areas and that location can be a barrier to anyone, regardless of ethnicity. Devolution is the most effective way to meet the needs of these deprived neighbourhoods and to ensure services work well together.
Department of Health [DH]	2009	Valuing People Now: a new three-year strategy for people with learning disabilities https://lx.iriss.org.uk/sites/default/files/resources/Valuing%20people%20now.pdf	The Valuing People national advocacy fund will focus on supporting advocacy to better support advocacy for people from black and minority ethnic communities. Chapter 1 Inclusivity • 1.1 All people with learning disabilities are supported to become empowered citizens. • 1.10 To ensure people with learning disabilities from black and minoritised groups do not face 'double-discrimination'. • 1.11 the Race Relations (amendment) Act (2000) requires all services to be compliant and public authorities must monitor their work for any adverse effect on race equality. • 1.12 Guidance on working with people from minority ethnic groups in rural areas can help local service planners and developers address this.

			• 1.13 creates a new programme of work: to raise awareness and design and commission services to ensure inclusion, develop and disseminate good practice to inform policy, in line with NAGLDE's (National Advisory Group on Learning Disability and Ethnicity) recommendations. It will also champion issues for people with more complex needs and people from black and minority ethnic groups and newly arrived communities and support, through deputy regional directors for Social Care and partnerships, regional and local work programmes to bring about service improvements to address the needs of these groups • 1.20 Recognises and values family carers as key partners in the delivery of this strategy. including families from ethnic minorities who are at greater risk of isolation. Chapter 2: Personalisation • 2.6 within the context of the transformation and personalisation agenda it is important that the issues specific to people with learning disabilities and their families are properly addressed. This is particularly the case for those with more complex needs and from black and minority ethnic and newly arrived communities. Chapter 4 People as citizens • 4.12 Hate crime - people with learning disabilities have a right to live in safety and to be taken seriously when they complain about abuse or report a crime against them. The lives of too many people with learning disabilities are constrained by experience of abuse and neglect and many people have been victims of hate crime. People from black and minority ethnic groups and newly arrived communities are particularly at risk of hate crime.

			Chapter 5 Making it happen • 5.28 Developing the workforce to deliver support locally for the most excluded groups of people (people with complex needs, behaviour which challenges, autistic spectrum conditions, mental health needs, or people from black and minority ethnic communities), in line with the Mansell report.
Department of Health [DoH]	2012	Transforming care: A national response to Winterbourne View Hospital: Department of Health Review Final Report https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/213215/final-report.pdf	No information in relation to people with learning disabilities from Black and minoritised communities.
Department of Health [DoH]	2013	Government response to the Confidential Inquiry into premature deaths of people with learning disabilities https://www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/governmentresponsefull.pdf	No information in relation to people with learning disabilities from Black and minoritised communities.
NHS England, Local Government Association [LGA] and the Association of Directors of Social Services [ADASS]	2015	Building the Right Support https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf	No information in relation to people with learning disabilities from Black and minoritised communities.
NHS England, Local Government Association [LGA] and the Association of Directors of Social Services [ADASS]	2015	Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition https://www.england.nhs.uk/wp-content/uploads/2015/10/service-model-291015.pdf	No information in relation to people with learning disabilities from Black and minoritised communities.

Department of Health [DoH]	2015	NHS Constitution for England (2015) https://www.gov.uk/government/publications/the-nhs-constitution-for-england	No information in relation to people with learning disabilities from Black and minoritised communities. Your rights: You have the right not to be unlawfully discriminated against in the provision of NHS services including on grounds of gender, race, disability, age, sexual orientation, religion, belief, gender reassignment, pregnancy and maternity or marital or civil partnership status.
NHS England	2015	Safeguarding vulnerable people in the NHS – Accountability and assurance framework https://www.england.nhs.uk/publication/safeguarding-children-young-people-and-adults-at-risk-in-the-nhs-safeguarding-accountability-and-assurance-framework/	No information in relation to people with learning disabilities from Black and minoritised communities.
NHS England, Association of Directors of Social Services [ADASS], Care Quality Commission [CQC], Department of Health [DoH], Health Education England [HEE], Local Government Association [LGA]	2015	Transforming care for people with learning disabilities – next steps https://www.england.nhs.uk/wp-content/uploads/2015/01/transform-care-nxt-stps.pdf	Whilst the report concerns transforming care for people with learning disabilities, it does not specifically mention people with learning disabilities from Black and minoritised communities.

Skills for Health, Skills for Care, Health Education England [HEE]	2016	Learning disabilities core skills education and training framework https://www.cppe.ac.uk/wizard/files/publications/leaflets/learning%20disabilities%20cstf.pdf	Acknowledges that learning disabilities affect people (children, young people and adults) from all cultural and ethnic backgrounds. Issues of cultural and ethnic diversity may have an impact on how people experience a learning disability, including the acceptance of the condition within their family or community. In addition, many of the characteristics covered by the Equality Act and related to the wider determinants of health can have a significant bearing on experiences of learning disabilities, including but not limited to a person (child, young person and adult) with a disability's sexuality, gender or geographical location.
Department for Work and Pensions [DWP], Department of Health and Social Care [DHSC]	2017	Improving lives: the future of work, health and disability (2017) https://www.gov.uk/government/publications/improving-lives-the-future-of-work-health-and-disability	People with learning disabilities mentioned extensively, but no information in relation to people with learning disabilities from Black and minoritised communities.
National Quality Board (2017)	2017	National guidance on learning from deaths https://www.england.nhs.uk/publication/national-guidance-on-learning-from-deaths/	Recommends: • In the LeDeR programme relating to the deaths of people with learning disabilities, a full multi-agency review is required if the criteria for the current themed priority review are met (death of a person from a Black and Minority Ethnic background or aged 18-24), or where an assessment of the care received by the person indicates deficiencies in one or more significant areas.

NHS England, Local Government Association [LGA], Association of Directors of Adult Social Services [ADASS]	2017	Transforming Care: service model specification https://www.england.nhs.uk/publication/transforming-care-service-model-specification-january-2017/	No information in relation to people with learning disabilities from Black and minoritised communities.
NHS Improvement	2018	The learning disability improvement standards for NHS trusts https://www.england.nhs.uk/learning-disabilities/about/resources/the-learning-disability-improvement-standards-for-nhs-trusts/	No information in relation to people with learning disabilities from Black and minoritised communities.
Department of Health and Social Care [DHSC]	2018	Government response to the Learning Disabilities Mortality Review (LeDeR) Programme 2nd annual report https://www.gov.uk/government/publications/government-response-to-the-learning-disabilities-mortality-review-leder-programme-2nd-annual-report	No information in relation to people with learning disabilities from Black and minoritised communities.
Department of Health and Social Care [DHSC]	2019	'Right to be heard': The Government's response to the consultation on learning disability and autism training for health and care staff https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/844356/autism-and-learning-disability-training-for-staff-consultation-response.pdf	No information in relation to people with learning disabilities from Black and minoritised communities.
NHS England	2019	The NHS Long Term Plan https://www.longtermplan.nhs.uk/	An acknowledgement of poor health outcomes in Black and minoritised groups but no specific reference to people with learning disabilities from these backgrounds

NHS England	2019	The NHS Long Term Plan Implementation framework https://www.longtermplan.nhs.uk/implementation-framework/	An acknowledgement of poor health outcomes in Black and minoritised groups but no specific reference to people with learning disabilities from these backgrounds
NHS England and NHS Improvement	2019	The National Learning Disability Mortality Review Programme (LeDeR), Action from learning report https://www.england.nhs.uk/publication/leder-action-from-learning/	Clinical Commissioning Groups and local LeDeR steering groups to use local population demographic data to compare trends within the population of people with learning disabilities. They should be able to evidence whether the number of deaths of people from Black, Asian and Minority Ethnic groups notified to LeDeR are representative of that area and use the findings to take appropriate action.
Skills for Care, Skills for Health	2019	Core Capabilities Framework for Supporting People with a Learning Disability https://www.skillsforhealth.org.uk/wp-content/uploads/2020/11/Learning-Disability-Framework-Oct-2019.pdf	The person or practitioner will: a) be aware of their own values and beliefs b) know what is meant by: • diversity • equality • inclusion • discrimination • ethnicity and religion.
Department of Health and Social Care [DHSC]	2020	The Government response to the third annual Learning Disabilities Mortality Review (LeDeR) Programme report https://www.gov.uk/government/publications/leder-third-annual-programme-report-government-response	Recommendation 4: Clinical Commissioning Groups and local LeDeR steering groups to use local population demographic data to compare trends within the population of people with learning disabilities. They should be able to evidence whether the number of deaths of people from Black, Asian and Minority Ethnic groups notified to LeDeR are representative of that area and use the findings to take appropriate action.

Department of Health and Social Care [DHSC]	2020	The Government Response to the Joint Committee on Human Rights reports on the Detention of Young People with Learning Disabilities and/or Autism and the implications of the Government's COVID-19 response https://www.gov.uk/government/publications/jchr-reports-on-the-detention-of-young-people-with-learning-disabilities-or-autism-government-response	Mentions of Government actions: In terms of improving the quality of advocacy services, we have committed to launch a pilot programme, in partnership with Local Authorities and others, to identify how to respond appropriately to the particular needs of individuals from ethnic minority backgrounds. DHSC have commissioned Public Health England to undertake a thorough analysis of the numbers of deaths of people with a learning disability, including looking at the age, gender and ethnicity of people with a learning disability who have died.
Department of Health and Social Care [DHSC]	2021	People at the Heart of Care: adult social care reform white paper https://www.gov.uk/government/publications/people-at-the-heart-of-care-adult-social-care-reform-white-paper	No information in relation to people with learning disabilities from Black and minoritised communities.
Gov.UK	2021	National Disability Strategy https://www.gov.uk/government/publications/national-disability-strategy	Aims to increase public awareness of autism and emphasise the diversity of the autistic community, including the presentation of autism in women and girls, the LGBT community, and autistic people from ethnic minority backgrounds. No information in relation to people with learning disabilities from Black and minoritised communities.
Department of Health and Social Care [DHSC] and Department for Education [DoE]	2021	The National Strategy for Autistic Children, Young People and Adults: 2021 to 2026 https://www.gov.uk/government/publications/national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026	Seeks to ensure the strategy covers the diversity of the autistic community, including the presentation of autism in women and girls, the LGBT community, and autistic people from ethnic minority groups.
Department of Health and Social Care [DHSC]	2022	Health and social care integration: joining up care for people, places and populations https://www.gov.uk/government/publications/health-and-social-care-integration-joining-up-care-for-people-places-and-populations	No information in relation to people with learning disabilities from Black and minoritised communities.

NHS England and partners	2022	Working in partnership with people and communities: statutory guidance https://www.england.nhs.uk/publication/working-in-partnership-with-people-and-communities-statutory-guidance/	Statutory guidance for integrated care boards, NHS trusts, foundation trusts and NHS England, supporting effective partnership working with people and communities to improve services and meet public involvement legal duties. Includes mention of importance of making reasonable adjustments for people with learning disabilities and autistic people, but no mentions of working in partnership with people with learning disabilities from Black and minoritised communities.
House of Commons Health and Social Care Committee	2022	The treatment of autistic people and people with learning disabilities: Government Response to the Committee's Fifth Report of Session 2021-22 https://committees.parliament.uk/committee/81/health-and-social-care-committee/news/172550/government-response-to-report-on-the-treatment-of-autistic-people-and-people-with-learning-disabilities-published/	One mention of Government action: Focused LeDeR reviews in respect of the death of a person from an ethnic minoirty
NHS England	2022	Learning from lives and deaths – People with a learning disability and autistic people (LeDeR): Action from learning report 2021/22 https://leder.nhs.uk/images/resources/Action-From-Learning-Report-2021-22.pdf	Case examples involving people with learning disabilities from Black and minoritised communities. Update on actions concerning racial inequalities: every death of person from a minority ethnic group has a focused LeDeR review; LeDeR reviewers should be representative of local population and understand local community's culture and beliefs; each ICB has a named lead to ensure challenges faced by people from minority ethnic groups in their local area are considered and addressed as part of LeDeR. Series of commissioned projects to identify and address the barriers faced by people with learning disabilities from minority ethnic groups.

Table C: Policies from elsewhere in the UK

Author	Year	Publication	Information in relation to people with learning disabilities from Black and minoritised communities
Scottish Government	2019	The Keys to Life. Strategy (2013) and Implementation Framework and Priorities 2019-2021 https://www.scld.org.uk/the-keys-to-life-implementation-framework-2019-2021/	The 2013 Keys To Life Strategy acknowledges people with learning disabilities from BME communities often face major barriers in accessing support and services that meet their needs. Carers and families of ethnic minority backgrounds have difficulty accessing information and services. The 2019-2021 Implementation Strategy and Priorities does not specifically recognise or mention people with learning disabilities from Black and minoritised communities.
Welsh Government	2018	Learning Disability – Improving Lives Programme https://gov.wales/learning-disability-improving-lives-programme	The programme does not specifically recognise or mention people with learning disabilities from Black and minoritised communities.
Welsh Government	2022	Learning Disability Policy - Strategic Action Plan 2022 -2026 https://gov.wales/learning-disability-strategic-action-plan-2022-2026	To consider the impact and effectiveness of learning disability policies on people with learning disabilities, their families and carers in the Black, Asian and Minority Ethnic community. In year one the Welsh Government and Learning Disability Ministerial Advisory Group will review the impact and effectiveness of current policies to ensure that the needs of individuals with a learning disability from the Black, Asian and Minority Ethnic communities are being met. Where gaps are identified - take action to ensure that Welsh Government policies fully meet the identified needs.
Northern Ireland Executive	2012-2015	Bamford Action Plan (2012-2015) https://www.health-ni.gov.uk/publications/bamford-action-plan-2012-15	No information in relation to people with learning disabilities from Black and minoritised communities.

Appendix 2: Detailed Information on Administrative Datasets

Table A: Administrative datasets – Children and Young People

Dataset	Source and links	Includes data on learning disability	Includes data on ethnicity	Includes demographic data	Includes geographical data	Includes data on service use	Includes data on health and wellbeing
Children looked after in England including adoptions	Department for Education https://explore-education-statistics.service.gov.uk/find-statistics/children-looked-after-in-england-including-adoptions/2021	No Category of need includes "Child's disability" as one of 8 categories of need (N1: abuse or neglect; N2: child's disability; N3: Parental illness or disability; N4: Family in acute stress; N5: Family dysfunction; N6: Socially unacceptable behaviour; N8: Absent parenting	Yes 19 ethnicity categories	Yes Age band Gender	Yes Region Local authority	Yes CLA placement provider CLA placement type CLA distance of placement from home CLA adopted CLA subject of a special guardianship order	Yes Offending rates Substance misuse Immunisations and annual health assessments Emotional and behavioural health (Strengths & Difficulties Questionnaire)

Special educational needs in England	Department for Education https://explore-education-statistics.service.gov.uk/find-statistics/special-educational-needs-in-england/2021-22 Covers children with special educational needs in: State-funded primary schools State-funded secondary schools State-funded special schools Non-maintained special schools Pupil referral units Independent schools	Yes SEN primary needs categories: Moderate Learning Difficulty (MLD) Severe Learning Difficulty (SLD) Profound Multiple Learning Difficulty (PMLD) Two levels of need: 1) Education, Health and Care Plan/ Statement 2) SEN Support	Yes 19 ethnicity categories	Yes Age Gender Eligibility for Free School Meals	Yes Region Local authority	Yes School type	No
Participation in education, training and employment	Department for Education https://www.gov.uk/government/statistics/participation-in-education-training-and-employment-2021	No	No	Yes Age Gender	No	Yes 16-18 year-old participation in education, training and employment of different types	No

Table B: Administrative datasets – Adult Social Care

Dataset	Source and links	Includes data on learning disability	Includes data on ethnicity	Includes demographic data	Includes geographical data	Includes data on service use	Includes data on health and wellbeing
Adult Social Care Survey	NHS Digital https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/social-care-user-surveys https://digital.nhs.uk/data-and-information/publications/statistical/personal-social-services-adult-social-care-survey Collected annually from samples of adults using social care support across England, via Councils with Social Services Responsibilities (CSSRs)	Yes PSR (Primary Support Reason) 1 Physical support 2 Sensory support 3 Support with memory and cognition 4 Learning disability support 5 Mental health support 6 Social support 99 Value suppressed Stratum 1 Learning Disability Support 2 18-64, excl Learning Disability 3 65+ in Residential Care, excl Learning Disability 4 65+ in Community, excl Learning Disability 99 Value suppressed	Yes ethgrp 1 White 2 Non-White 3 Refused/ Prefer not to say/ Not stated 99 Value suppressed	Yes gender 1 Male 2 Female 3 Other 4 Value suppressed agegrp 1 18-64 2 65 and over 99 Value suppressed	Yes cassr Region Local authority	Yes Support Setting 1 Community 2 Residential Care 3 Nursing Care 99 Value suppressed Mechanism Delivery 1 Direct Payment Only 2 Part Direct Payment 3 LA Managed Personal Budget 4 LA Commissioned Support Only 5 Not applicable.	Yes 39 questions on aspects of health, wellbeing, and satisfaction with social care support. Includes: Overall satisfaction with care and support services received Self-rated quality of life Self-rated general health Pain or discomfort Anxiety or depression

Personal Social Services Survey of Adult Carers in England	NHS Digital https://digital.nhs.uk/data-and-information/publications/statistical/personal-social-services-survey-of-adult-carers/england-2021-22 Collected every two years from samples of adult carers of adults using social care support in England, via Councils with Social Services Responsibilities (CSSRs)	Yes SACE dataset Q24d: Do you (the carer) have any of the following? A learning disability or difficulty [SACE annex tables include Primary Support Reason for cared-for person and more detailed carer ethnicity information, but not in a format that allows for comparative analysis by ethnicity]	Yes ethgrp (of carer) 1 White 2 Non-White 3 Refused/Not stated 99 Record suppressed	Yes gender (of carer) 1 Male 2 Female 3 Other 99 Record suppressed agegrp (of carer) 1 18-64 2 65 and over 99 Record suppressed Q19a-Q19h – carer employment Q24a-Q24g – longstanding illness or disability Q1 (age of cared-for person) 1 18-64 2 65 and over	Yes cassr Region Local authority	Yes SupportToCarer 1 Direct payment only 2 Part direct payment 3 CASSR managed personal budget 4 CASSR commissioned support only 5 Information, advice and other universal services/signposting 6 No direct support provided to carer SupportInv CaredFor 1 Respite services provided 2 No respite services provided FundStatus CaredFor 1 Supported and funded by LA 2 Full-cost 3 Self-funded 4 Cared-for person not known to LA 5 Cared-for person known by does not receive council services	Yes 43 questions on aspects of carer health, wellbeing, and satisfaction with social care support. Includes: In the last 12 months, health affected by caring role • Feeling tired • Feeling depressed • Loss of appetite • Disturbed sleep • General feeling of stress • Physical strain • Short tempered/ irritable • Had to see own GP • Developed own health conditions • Made existing condition worse • Other • No, none of these

						Q5a-Q5j Has cared-for person used any of the support or services listed below in the last 12 months: Support/service allowing you to take a break from caring at short notice/in an emergency Support/services allowing you to take a break for more than 24 hours Support/services allowing to have a rest from caring for 1-24 hours Personal assistant Home care/home help Day centre or day activities Lunch club Meals services Equipment/home adaptation Lifeline alarm Permanently resident in care home	

						Q6a-Q6d Have you used any of the support or services listed below, to help you as a carer over the last 12 months Info and advice Support from carers groups or someone to talk to in confidence Training for carers Support to keep you in employment	
Adult Social Care Finance Return	NHS Digital Mainly reported in the Adult Social Care Activity and Finance Report, England https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-activity-and-finance-report/2020-21 (for 2020-21)	Yes Primary Support Reason - Learning Disability Support	No	Yes Age band	Yes Region Local authority	Yes Net and gross expenditure Unit costs Requests for support from new clients and what happened next Care type	No

Short And Long Term (SALT) Social Care Activity	NHS Digital Mainly reported in the Adult Social Care Activity and Finance Report, England https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-activity-and-finance-report/2020-21 (for 2020-21) More detailed breakdowns of employment and housing data for adults with learning disabilities aged 18-64 available in CSV files Publicly available crosstabs do not include any analysis of ethnicity by service access/use for people with learning disabilities	Yes Primary Support Reason - Learning Disability Support	Yes White Mixed/ Multiple ethnic groups Asian/ Asian British Black/ African/ Caribbean/ Black British Other Ethnic Group No data	Yes Age band Gender	Yes Region Local authority	Yes Short or long-term social care Type of personal budget Employment situation (people with learning disabilities aged 18-64) Living situation (people with learning disabilities aged 18-64)	No

Safeguarding Adults	NHS Digital https://digital.nhs.uk/data-and-information/publications/statistical/safeguarding-adults/2021-22 (for 2021-22) CSV file does not allow for the breakdown of learning disability by ethnicity	Yes (within the subcategory variable in CSV file) Learning Disability Support Learning, Developmental or Intellectual Disability (Learning Disability)	Yes (within the subcategory variable in CSV file) White Mixed/ Multiple ethnic groups Asian/ Asian British Black/ African/ Caribbean/ Black British Other Ethnic Group Refused Undeclared	Yes Age band Gender	Yes Region Local authority	Yes Safeguarding Concerns Section 42 Enquiries Type of risk for concluded Section 42 enquiries Locations of risk for concluded Section 42 enquiries Other Enquiries Safeguarding Adult Reviews	No

Deprivation of Liberty Safeguards, England	NHS Digital https://digital.nhs.uk/data-and-information/publications/statistical/mental-capacity-act-2005-deprivation-of-liberty-safeguards-assessments/2021-22 (for 2021-22)	No	Yes (within the category/ measure variables in CSV file) White Mixed/ Multiple ethnic group Asian/ Asian British Black/ Black British Other ethnic origin Not stated Undeclared/ unknown Invalid ethnicity code	Yes Age band Gender Sexual orientation	Yes Region Local authority	Yes DoLS applications received (urgent/ standard) DoLS applications completed DoLS applications not completed DoLS application granted DoLS application not granted (by reason not granted) Timeframes CQC service type (acute hospitals, mental health, care homes-nursing, care homes-residential, other services, blank/ invalid)	No

Table C: Administrative datasets – Health and Health Care

Dataset	Source and links	Includes data on learning disability	Includes data on ethnicity	Includes demographic data	Includes geographical data	Includes data on service use	Includes data on health and wellbeing
Health and Care of People with Learning Disabilities Experimental Statistics	NHS Digital https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities Reported annually using GP records of 56.0% of all patients with a GP in England (2020-2021).	Yes Uses GP-registered learning disabilities Also contains information on people registered with GPs as autistic people	No [although ethnicity is included in GP records and could be added to this dataset]	Yes Age band Sex	Yes Region Sustainability and Transformation Partnership Clinical Commissioning Group	Yes Anti-depressants (with and without a depression diagnosis) Antipsychotics (with and without a diagnosis of severe mental health problem) Benzodiazepines Cervical cancer smear Colorectal cancer screening Epilepsy drugs On drug treatment for epilepsy Palliative care	Yes ADHD Asthma Blood pressure BMI underweight; healthy weight; overweight; obese Cancer Chronic kidney disease COPD Coronary heart disease Dementia Depression Diabetes non-Type 1, Type 1

						For people with learning disabilities only: Flu jabs Health check Health check with action plan	Diabetes mellitus Epilepsy Heart failure Hypertension Hypothyroidism Mental health Stroke or Transient Ischaemic Attack For people with learning disabilities only: Constipation Down's Syndrome Down's Syndrome and dementia Down's Syndrome and hyperthyroidism Dysphagia GORD

Quality and Outcomes Framework (QOF)	NHS Digital https://digital.nhs.uk/data-and-information/publications/statistical/quality-and-outcomes-framework-achievement-prevalence-and-exceptions-data/2021-22 Data provided annually by 97.5% of GP practices in England (2021-2022)	Yes Uses GP-registered learning disabilities Number and prevalence (against GP total list size) of people with learning disabilities	No	No	Yes Integrated Care Board (ICB) Sub ICB location Primary Care Network GP practice	Yes If the GP practice has a register of people with learning disabilities	No
Learning Disabilities Health Check Annual Scheme	NHS Digital https://digital.nhs.uk/data-and-information/publications/statistical/learning-disabilities-health-check-scheme Data published monthly	Yes Statistics concern annual health checks for people with learning disabilities flagged on GP registers	No	Yes Age band	Yes Region Integrated Care Board (ICB) Sub-ICB Primary Care Network (PCN) GP practice	Yes Number of people with learning disabilities who received an annual health check Percentage of people with learning disabilities on the GP register who received an annual health check	No

Learning disability improvement standards for NHS Trusts	NHS Improvement / NHS England https://www.england.nhs.uk/learning-disabilities/about/resources/the-learning-disability-improvement-standards-for-nhs-trusts/#improvement-standards National benchmarking exercises conducted by NHS Benchmarking Network https://www.nhsbenchmarking.nhs.uk/news/learning-disabilities-improvement-standards-year-3-published (Year 3, 2020)	Benchmarking exercise reports practices relating to people with learning disabilities collected from organisations, findings from a survey of over 7,000 staff, and findings from a survey of over 2,500 people with learning disabilities	No	No	Yes Individual-level NHS Trust data shared with NHS Trusts	Yes 140 indicators in total in Year 3 benchmarking. One indicator makes reference to ethnicity: Ethnicity of staff in specialist learning disability service staff (headcount) 81% White/White British/White Other 5% Asian/Asian British 6% Black/Black British 1% Mixed race 1% Other ethnicity 6% Unknown/not stated	No

Assuring Transformation	NHS Digital https://digital.nhs.uk/data-and-information/publications/statistical/learning-disability-services-statistics Monthly data on people with learning disabilities and autistic people in inpatient services provided by sub-Integrated Care Boards (commissioners) – can include people in inpatient services outside England commissioned by English health service commissioners Publicly available crosstabs do not include any analysis of demographic, service use or diagnostic indicators by ethnicity	Yes Learning disability only Autism only Learning disability and autism None of the above	Yes White Mixed Asian or Asian British Black or Black British Other ethnic groups Not stated/ not known	Yes Age band Gender	Yes NHS Regional Team Integrated Care System (ICS)	Yes Multiple indicators relating to legal status, type of service, ward security, pre-admission and admission, care plan, advocacy, reviews, planned and actual transfers/ discharges, deaths, length of stay, distance from home, provider organisation	Yes Diagnosis on admission (9 categories) Additional diagnosis since admission (9 categories)

Mental Health Services Dataset (MHSDS)	NHS Digital https://digital.nhs.uk/data-and-information/publications/statistical/learning-disability-services-statistics Monthly data on people with learning disabilities and autistic people in all mental health inpatient services drawn from continuous data provided by mental health service providers. Can include people in inpatient units in England commissioned by organisations outside England Publicly available crosstabs do not include any analysis of demographic or service use indicators by ethnicity	Yes All people in dataset are flagged as a person with learning disabilities or an autistic person	Yes White Mixed Asian Black Other Not stated Unknown	Yes Age band Gender	Yes Commissioning CCG NHSE Commissioner NHS Trust Commissioner	Yes Multiple indicators relating to legal status, type of service, ward security, pre-admission and admission, actual transfers/discharges, deaths, length of stay, distance to treatment, restrictive interventions, provider organisation	No

Table D: Administrative datasets – Benefits

Dataset	Source and links	Includes data on learning disability	Includes data on ethnicity	Includes demographic data	Includes geographical data	Includes data on service use	Includes data on health and wellbeing
Attendance Allowance	DWP Stat-Xplore https://stat-xplore.dwp.gov.uk/webapi/jsf/login.xhtml Quarterly data from 2002	Partly Main disabling condition: Learning difficulties (a broader category than learning disabilities)	No	Yes Gender Age Main disabling condition	Yes Region Council Parliamentary constituency	Yes Cases with entitlement Cases in payment AA award type Duration of current claim	No
Disability Living Allowance	DWP Stat-Xplore https://stat-xplore.dwp.gov.uk/webapi/jsf/login.xhtml Quarterly data from 2002	Partly Main disabling condition: Learning difficulties (a broader category than learning disabilities)	No	Yes Gender Age Main disabling condition	Yes Region Council Parliamentary constituency	Yes Cases with entitlement Cases in payment Care award type Mobility award type Duration of current claim	No

Personal Independence Payment	DWP Stat-Xplore https://stat-xplore.dwp.gov.uk/webapi/jsf/login.xhtml Monthly data from 2013	Yes Disability – Psychiatric disorders – Learning disability global (with three sub-categories: Down's syndrome; Fragile X syndrome; Learning disability other/ type not known)	No	Yes Gender Age Disability	Yes Region Council Parliamentary constituency	Yes Cases with entitlement DLA status Mobility award status Duration of claim	Yes ICD summary code
Carer's Allowance	DWP Stat-Xplore https://stat-xplore.dwp.gov.uk/webapi/jsf/login.xhtml Quarterly data from 2003	No (of carer or person being cared for)	No	Yes Age of carer Gender of carer	Yes Region Council Parliamentary constituency	Yes Cases with entitlement Cases in payment Grouped amount of benefit Duration of claim	
Employment and Support Allowance	DWP Stat-Xplore https://stat-xplore.dwp.gov.uk/webapi/jsf/login.xhtml Quarterly data from 2008	No	Yes Detailed and summary	Yes Age Gender If person has a partner	Yes Region Council Parliamentary constituency	Yes Payment type Phase of ESA claim Grouped amount of benefit	Yes ICD summary code

Income Support	DWP Stat-Xplore https://stat-xplore.dwp.gov.uk/webapi/jsf/login.xhtml Quarterly data from 1999	No	No	Yes Age Gender Number of child dependants If the person has a partner	Yes Region Council Parliamentary constituency	Yes Grouped amount of benefit Minimum income guarantee Duration of current claim	No
Jobseeker's Allowance	DWP Stat-Xplore https://stat-xplore.dwp.gov.uk/webapi/jsf/login.xhtml Quarterly data from 1999	No	Yes Detailed and summary	Yes Age Gender Age of youngest child Number of child dependants If the person has a partner	Yes Region Council Parliamentary constituency	Yes Grouped amount of benefit Duration of current claim	No
Universal Credit	DWP Stat-Xplore https://stat-xplore.dwp.gov.uk/webapi/jsf/login.xhtml Monthly data from 2013	No	No	Yes Age Gender Employment indicator	Yes Region Council Parliamentary constituency Postcode area	Yes Conditionality regime Duration Claims made; Households; People; Starts	No

Housing Benefit	DWP Stat-Xplore https://stat-xplore.dwp.gov.uk/webapi/jsf/login.xhtml Monthly data from 2008	No	No	Yes Age Gender (single claimants only) Family type Number of child dependants Number of non-dependants Housing type Employment Status	Yes Region Council Parliamentary constituency Eurostat NUTS areas Travel To Work Areas (TTWAs) UK International Territorial Levels (ITLs)	Yes Weekly Award Amount (bands) Entitled Bedrooms (LHA only) Pay Destination	No
Pension Credit	DWP Stat-Xplore https://stat-xplore.dwp.gov.uk/webapi/jsf/login.xhtml Quarterly data from 2003	No	No	Yes Age Gender If the person has a partner	Yes Region Council Parliamentary constituency	Yes Grouped amount of benefit Type of pension credit Duration of claim	No
State Pension	DWP Stat-Xplore https://stat-xplore.dwp.gov.uk/webapi/jsf/login.xhtml Quarterly data from 2002	No	No	Yes Age Gender Country where person is living Dependency increase	Yes Region Council Parliamentary constituency	Yes Grouped amount of benefit Category of pension	No

Appendix 2b: Examples of findings from administrative datasets

Table E: Special Educational Needs in England 2021-2022

Ethnicity	SEN Primary Need Category (number, percentage of children in SEN category)						TOTAL pupils in schools (number, percentage)
	Moderate Learning Difficulty (MLD) EHCP/Statement	Moderate Learning Difficulty (MLD) SEN support	Severe Learning Difficulty (SLD) EHCP/ Statement	Severe Learning Difficulty (SLD) SEN support	Profound Multiple Learning Difficulty (PMLD) EHCP/Statement	Profound Multiple Learning Difficulty (PMLD) SEN support	
White							
White British	23,578 (73.6%)	136,162 (69.2%)	19,958 (63.4%)	1,498 (61.5%)	5,752 (56.7%)	440 (57.2%)	5,379,748 (63.9%)
Traveller of Irish heritage	36 (0.1%)	497 (0.3%)	44 (0.1%)	5 (0.2%)	9 (0.1%)	0 (0.0%)	6,903 (0.1%)
Irish	77 (0.2%)	479 (0.2%)	56 (0.2%)	6 (0.2%)	24 (0.2%)	0 (0.0%)	21,495 (0.3%)
Gypsy/Roma	163 (0.5%)	2,056 (1.0%)	133 (0.4%)	18 (0.7%)	27 (0.3%)	5 (0.7%)	27,359 (0.3%)
Any other White background	1,175 (3.7%)	10,400 (5.3%)	1,513 (4.8%)	125 (5.1%)	570 (5.6%)	42 (5.5%)	575,540 (6.8%)

Appendix 2b: Examples of findings from administrative datasets

Black							
Black Caribbean	349 (1.1%)	2,317 (1.2%)	332 (1.1%)	28 (1.2%)	96 (0.9%)	5 (0.7%)	82,402 (1.0%)
Black African	932 (2.9%)	6,046 (3.1%)	1,649 (5.2%)	126 (5.2%)	508 (5.0%)	43 (5.6%)	338,614 (4.0%)
Any other Black background	237 (0.7%)	1,334 (0.7%)	393 (1.2%)	23 (0.9%)	107 (1.1%)	4 (0.5%)	65,501 (0.8%)
Asian							
Indian	533 (1.7%)	3,513 (1.8%)	820 (2.6%)	81 (3.3%)	294 (2.9%)	22 (2.9%)	289,179 (3.4%)
Pakistani	1,358 (4.2%)	11,504 (5.8%)	1,900 (6.0%)	137 (5.6%)	1,001 (9.9%)	60 (7.8%)	380,781 (4.5%)
Bangladeshi	366 (1.1%)	2,679 (1.4%)	660 (2.1%)	64 (2.6%)	323 (3.2%)	22 (2.9%)	151,613 (1.8%)
Chinese	47 (0.1%)	215 (0.1%)	125 (0.4%)	1 (0.0%)	27 (0.3%)	2 (0.3%)	48,396 (0.6%)
Any other Asian background	470 (1.5%)	2,426 (1.2%)	729 (2.3%)	53 (2.2%)	297 (2.9%)	17 (2.2%)	170,572 (2.0%)
Mixed							
White and Black Caribbean	602 (1.9%)	3,915 (2.0%)	450 (1.4%)	48 (2.0%)	138 (1.4%)	17 (2.2%)	133,504 (1.6%)
White and Black African	236 (0.7%)	1,522 (0.8%)	279 (0.9%)	26 (0.1%)	78 (0.8%)	9 (1.2%)	76,262 (0.9%)
White and Asian	329 (1.0%)	2,278 (1.2%)	416 (1.3%)	26 (0.1%)	132 (1.3%)	14 (1.8%)	134.821 (1.6%)
Any other mixed background	593 (1.8%)	3,588 (1.8%)	822 (2.6%)	60 (2.5%)	289 (2.9%)	20 (2.6%)	213,597 (2.5%)

Any other ethnic group							
Any other ethnic group	443 (1.4%)	3,725 (1.9%)	684 (2.2%)	67 (2.8%)	268 (2.7%)	28 (3.6%)	185,355 (2.2%)
Unclassified							
Unclassified	533 (1.7%)	2,753 (1.4%)	541 (1.7%)	42 (1.7%)	168 (1.7%)	19 (2.5%)	136,371 (1.6%)
TOTAL	**32,057**	**197,409**	**31,504**	**2,434**	**10,108**	**769**	**8,418,013**

Table F: Adult Social Care Survey 2020/21 - For those with a Primary Support Reason of Learning Disability

	Ethnicity			
	White	Non-White	Refused/ Prefer not to say/ Not stated	Total
Gender				
Male	2,644 (59.8%)	476 (62.0%)	62 (68.1%)	3,182 (60.3%)
Female	1,778 (40.2%)	292 (38.0%)	29 (31.9%)	2,099 (39.7%)
Age group				
18-64	3,896 (81.9%)	768 (100%)	91 (100%)	4,755 (90.0%)
65+	526 (11.9%)	0 (0%)	0 (0%)	526 (10.0%)
Support setting				
Community	3,820 (86.4%)	725 (94.4%)	91 (100%)	4,636 (87.8%)
Residential care	602 (13.6%)	43 (5.6%)	0 (0%)	645 (12.2%)
Mechanism of delivery				
Direct Payment Only	1,019 (23.0%)	315 (41.0%)	40 (44.0%)	1,374 (26.0%)
Part Direct Payment	407 (9.2%)	72 (9.4%)	4 (4.4%)	483 (9.1%)
LA Managed Personal Budget	2,199 (49.7%)	302 (39.3%)	38 (41.8%)	2,539 (48.1%)
LA Commissioned Support Only	248 (5.6%)	36 (4.7%)	9 (9.9%)	293 (5.5%)
Not applicable	549 (12.4%)	43 (5.6%)	0 (0.0%)	592 (11.2%)

Appendix 2b: Examples of findings from administrative datasets

Self-rated quality of life				
So good, it could not be better or very good	676 (40.0%)	74 (31.8%)	12 (46.2%)	762 (39.1%)
Good	672 (39.8%)	98 (42.1%)	7 (26.9%)	777 (39.9%)
Alright	311 (18.4%)	58 (24.9%)	6 (23.1%)	375 (19.3%)
Bad	21 (1.2%)	2 (0.9%)	0 (0.0%)	23 (1.2%)
Very bad or So bad, it could not be worse	8 (0.5%)	1 (0.4%)	1 (3.8%)	10 (0.5%)
Self-rated general health				
Very good	793 (46.8%)	71 (31.1%)	10 (38.5%)	874 (44.9%)
Good	449 (26.5%)	80 (35.1%)	8 (30.8%)	537 (27.6%)
Fair	356 (21.0%)	61 (26.8%)	4 (15.4%)	421 (21.6%)
Bad	84 (5.0%)	14 (6.1%)	4 (15.4%)	102 (5.2%)
Very bad	12 (0.7%)	2 (0.9%)	0 (0.0%)	14 (0.7%)
Self-rated pain or discomfort today				
No pain or discomfort	1,158 (68.6%)	143 (64.4%)	18 (69.2%)	1,319 (68.1%)
Moderate pain or discomfort	468 (27.7%)	71 (32.0%)	6 (23.1%)	545 (28.2%)
Extreme pain or discomfort	62 (3.7%)	8 (3.6%)	2 (7.7%)	72 (3.7%)
Self-rated anxiety or depression today				
Not anxious or depressed	1,010 (60.3%)	135 (62.2%)	16 (61.5%)	1,161 (60.6%)
Moderately anxious or depressed	596 (35.6%)	75 (34.6%)	8 (30.8%)	679 (35.4%)
Extremely anxious or depressed	68 (4.1%)	7 (3.2%)	2 (7.7%)	77 (4.0%)

Table G: Personal Social Services Survey of Adult Carers in England 2021-2022 - For those where the carer self-reports their own Learning disability or difficulty

	Ethnicity of carer			
	White	Non-White	Refused/ Prefer not to say/ Not stated	Total
Gender (of carer)				
Male	358 (37.6%)	59 (23.1%)	26 (45.6%)	443 (34.7%)
Female	595 (62.4%)	196 (76.9%)	31 (54.4%)	822 (64.4%)
Age group (of carer)				
18-64	637 (67.5%)	192 (77.4%)	31 (55.4%)	860 (68.3%)
65+	307 (32.5%)	56 (22.6%)	25 (44.6%)	388 (30.8%)
Cared-for person lives:				
With carer	794 (86.8%)	219 (88.7%)	40 (75.5%)	1,062 (86.6%)
Elsewhere	121 (13.2%)	28 (11.3%)	13 (24.5%)	164 (13.4%)
In the last 12 months, has caring caused the carer any financial difficulties				
No, not at all	436 (47.1%)	64 (25.8%)	25 (43.1%)	528 (42.5%)
Yes, to some extent	334 (36.1%)	132 (53.2%)	25 (43.1%)	495 (39.8%)
Yes, a lot	155 (16.8%)	52 (21.0%)	8 (13.8%)	220 (17.7%)
In the last 12 months, has your health been affected by your caring role in any of the ways listed below:				
Feeling tired	712 (76.7%)	183 (72.9%)	42 (72.4%)	947 (75.8%)
Feeling depressed	511 (55.1%)	124 (49.4%)	37 (63.8%)	680 (54.4%)
Loss of appetite	232 (25.0%)	53 (21.1%)	15 (25.9%)	302 (24.2%)
Disturbed sleep	585 (63.0%)	160 (63.7%)	35 (60.3%)	788 (63.1%)
General feeling of stress	584 (62.9%)	151 (60.2%)	37 (63.8%)	780 (62.4%)
Physical strain	378 (40.7%)	109 (43.4%)	22 (37.9%)	515 (41.2%)
Short-tempered/irritable	421 (45.4%)	76 (30.3%)	24 (41.4%)	526 (42.1%)
Had to see own GP	297 (32.0%)	103 (41.0%)	12 (20.7%)	415 (33.2%)
Developed own health conditions	288 (31.0%)	79 (31.5%)	19 (32.8%)	390 (31.2%)
Made an existing condition worse	293 (31.6%)	79 (31.5%)	16 (27.6%)	394 (31.5%)
Other	60 (6.5%)	21 (8.4%)	3 (5.2%)	85 (6.8%)
No, none of these	80 (8.6%)	28 (11.2%)	4 (6.9%)	113 (9.0%)

Table H: People with learning disabilities and/or autistic people in inpatient services in England – Assuring Transformation (rounding to the nearest 5)

Ethnicity	Date								
	March 2015	March 2016	March 2017	March 2018	March 2019	March 2020	March 2021	March 2022	Aug 2022
White	2,285 (79%)	2,225 (79%)	2,140 (79%)	2,015 (78%)	1,900 (77%)	1,755 (78%)	1,735 (78%)	1,660 (78%)	1,515 (77%)
Mixed	70 (2%)	55 (2%)	60 (2%)	60 (2%)	70 (3%)	55 (2%)	60 (3%)	55 (3%)	55 (3%)
Asian or Asian British	100 (3%)	100 (4%)	85 (3%)	90 (3%)	75 (3%)	70 (3%)	75 (3%)	75 (3%)	65 (3%)
Black or Black British	130 (5%)	135 (5%)	125 (5%)	125 (5%)	125 (5%)	110 (5%)	115 (5%)	115 (5%)	110 (5%)
Other ethnic groups	15 (1%)	25 (1%)	25 (1%)	30 (1%)	20 (1%)	20 (1%)	20 (1%)	15 (1%)	15 (1%)
Not stated/ not known	300 (10%)	280 (10%)	275 (10%)	260 (10%)	275 (11%)	240 (11%)	215 (10%)	215 (10%)	215 (11%)
TOTAL	**2,900**	**2,820**	**2,715**	**2,575**	**2,465**	**2,250**	**2,225**	**2,135**	**1,970**

Table E: People with learning disabilities and/or autistic people in inpatient services in England – Mental Health Services Dataset (rounding to the nearest 5)

Ethnicity	Date					
	March 2018	March 2019	March 2020	March 2021	March 2022	June 2022
White	2,625 (75%)	2,665 (74%)	2,500 (77%)	2,520 (76%)	2,710 (76%)	2,535 (75%)
Mixed	90 (3%)	145 (4%)	95 (3%)	110 (3%)	145 (4%)	130 (4%)
Asian	155 (4%)	180 (5%)	145 (4%)	170 (5%)	190 (5%)	180 (5%)
Black	285 (8%)	320 (9%)	220 (7%)	225 (7%)	215 (6%)	220 (7%)
Other	60 (2%)	65 (2%)	55 (2%)	60 (2%)	50 (1%)	60 (2%)
Not Stated	125 (4%)	115 (3%)	105 (3%)	120 (4%)	135 (4%)	125 (4%)
Unknown	165 (5%)	125 (3%)	135 (4%)	105 (3%)	130 (4%)	125 (4%)
TOTAL	**3,540**	**3,615**	**3,260**	**3,310**	**3,575**	**3,370**

Appendix 3:

Table A: Details of the electronic database search.

Search terms	Terms in the title, abstract or source of the article: “Learning Disability” and related terms AND “Ethnic minority” and related terms AND “Health and Healthcare” and related terms AND United Kingdom” and related terms
Electronic databases	Medline, PsycINFO, and Cinahl
Other methods used for identifying relevant research	Reference checking and hand searching of these. Review of LeDeR reports.
Roles of reviewers	Main reviewers: KU, CR, ND, SF, NCM, UC All abstracts and full-text articles were independently screened twice by two of the reviewers. KU, ND, CR, NCM, UC performed analysis.

Table B: Inclusion criteria for studies.

Criteria for including studies in the review	
i. Population	People from ethnic minorities with a learning disability
ii. Interventions or exposures	Health and care services
iii. Comparisons or control groups	People from the White British ethnic group
iv. Outcomes of interest	Access, patient experience and health (physical and mental) outcomes
v. Setting	All care settings in the UK
vi. Study designs	All study designs except case studies involving less than 5 participants
vii. Dates of publication	All dates from 1990 to June 2022

Table C: Exclusion criteria for studies.

Criteria for excluding studies in the review	
i. Language	Languages other than English
ii. Full-text unavailable	Incomplete articles or conference/meeting abstracts
iii. Publication date	Published before 1990
iv. Inadequate sample size	Any study with a sample size of less than 5 for participants from ethnic minority communities
v. Other populations	• Studies on conditions where Learning Disability cannot be assumed (e.g., cerebral palsy) where results not disaggregated for people with a Learning Disability
vi. Non-original studies	Reviews, letters, commentaries, editorials
vii. Other outcomes	• Studies where reported outcomes are not direct indicators of access, experience or physical/mental health e.g. general morale, self-esteem, quality of life (QoL) unless a specific health related QoL domain reported, social inclusion • Studies relating to challenging behaviour that do not include measures of psychopathology to differentiate challenging behaviour that functions as an indicator of mental ill health from challenging behaviour related to, for example, physical conditions and pain

Data extraction

The full text of included studies was retrieved, and the data were extracted and recorded onto an Excel spreadsheet, which included: article identifiers (leading author and year of publication), setting (e.g. community, primary care, secondary care), focus of the article, sample size, participant demographics (ethnic group, age range, percentage male), design of study (e.g. RCT, case-control, cohort, qualitative), limitations, key findings and outcome(s) reported (access, experience or health outcome). These included studies were separated into two tables which focused on studies which utilised a quantitative or qualitative/mixed-methods design.

Figure A: Identification of studies.

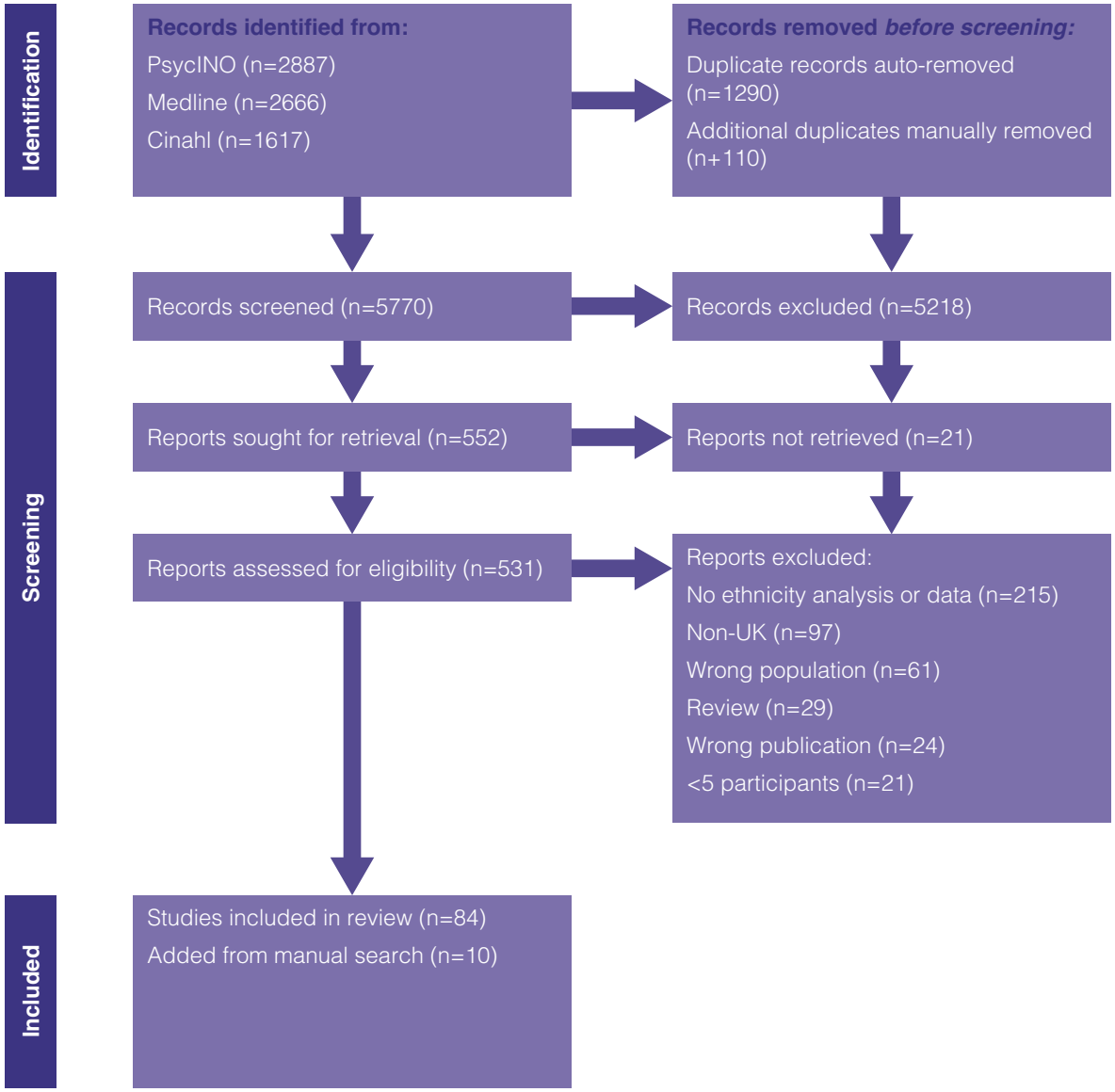


Table D: Studies included in the review, first author and year, separated by access, experience and outcomes.

Theme	Relevant studies (study number, first author and year)
Access	2 (Ali 2013), 4 (Bhaumik 2011), 7 (Caton 2007), 58 (Hatton 1998), 16 (Heer 2016), 18 (Chauhan 2012), 19 (Hubert 2006), 24 (McClimens 2013), 26 (Raghavan 2007), 27 (Russ 2021), 30 (Terashima 2011), 37 (Bouras 2003), 41 (Chaplin 1996), 51 (Dura-Vila 2009), 52 (Ellis 2008), 67 (L'Esperance 2021), 70 (Maitland 2006), 73 (McGrother 2002), 76 (O'Hara 2003), 77 (Parrott 2008), 79 (Raghavan 2009), 82 (Tsakanikos 2010)
Experience	1 (Akbar, 2020), 2 (Ali 2013), 3 (Azmi 1997), 5 (Bhardwaj 2018), 4 (Bhaumik 2011), 6 (Bonell 2011), 36 (Bonell, 2012), 8 (Chinn 2011), 9 (Craig 2006), 10 (Croot 2012a), 11 (Croot 2012b), 12 (Dobson 2002), 13 (Durling, 2018), 58 (Hatton 1998), 14 (Hatton 2010), 15 (Heer 2015), 16 (Heer 2016), 17 (Hersov 2007), 18 (Chauhan 2012), 19 (Hubert 2006), 20 (Kramer-Roy 2012), 21 (Larkin 2018), 22 (Malik 2017), 23 (McCarthy 2021), 25 (Munroe 2016), 26 (Raghavan 2007), 28 (Sandhu 2017), 29 (Sham 1996), 31 (Tuffrey-Wijne 2017), 35 (Bone 2014), 48 (Devapriam 2008), 55 (Emerson 2004), 69 (Liverpool 2021), 74 (Morris 2021), 81 (Sturmey 2009)
Outcomes	32 (Ainsworth 2001), 33 (Beer 2005), 34 (Bhaumik 2008), 38 (Carey 2021), 39 (Chadwick 2005), 40 (Chaplin 2017), 42 (Chen 2020), 43 (Chitsabesan 2006), 44 (Cummins 2021), 45 (Curtis 2022), 46 (Das-Mushi 2021), 47 (Davis 1991), 49 (Doshi 2009), 50 (Dunkley 2017), 53 (Emerson 2012), 54 (Emerson 1997), 55 (Emerson 2004), 56 (Emerson 2005), 57 (Emerson 2007), 59 (Hatton 2009), 60 (Hatton 2021), 61 (Johnson 2015), 62 (Joy 2020), 63 (Kerr 2001), 64 (Kiani 2013), 65 (Kroll 2002), 66 (Leese 2006), 68 (Linehan 2002), 71 (Marr 2001), 72 (Masefield 2022), 73 (McGrother 2002), 74 (Morris 2021), 75 (Morton 2002), 76 (O'Hara 2003), 77 (Parrott 2008), 78 (Parry 2021), 80 (Ruane 2019), 81 (Sturmey 2009), 82 (Tsakanikos 2010), 83 (Tyrer 2006), 84 (Tyrer 2007), 85 (Tyrer 2019), 86 (Tyrer 2020), 87 (Verity 2021), 88 (Winstone 2017), 89 (Wood, 2005)

Literature included in the scoping review.

Table E: Qualitative and mixed methods papers included in the review.

ID, First Author and Year	Setting	Focus	Design	Key sample features	Sample size	Ethnic categories used for analysis	Age range	% male	Relevant out-come measures	Key findings
1. Akbar 2020	Education and community: Two local authorities in the North of England	Explored parents' experiences of having a child with special educational needs and disability	Interviews and thematic analysis	Pakistani heritage caregivers who have a child with a developmental disability and a statutory identification of need for SEND	10	Pakistani: 100%	21 - 55	20%	Themes identified through interviews	Hidden disabilities were identified as more difficult to understand and seek support for. Parents found stigma to be a source of significant stress which led to strained marital relationships, though faith was a protective factor. Barriers to accessing special education services were language, perceived power differentials and mistrust.

2. Ali 2013	Community: England: London Sussex, Surrey, Somerset, Kent, Notting- hamshire and Lincolnshire	Explored experiences of barriers to service access for people with a learning disability	Semi-structured interviews and thematic analysis	Dyads of people with mild or moderate learning disability and their carers	29 (14 people with a learning disability, 15 carers)	White: 62% Indian:17% Pakistani: 21%	Learning disability: 23-57 Carers: 28-72	Learning disability: 50% Carers: 6.7%	Themes identified through semi-structured interviews	Half the participants thought the person with a learning disability had been treated unfairly or discriminated against by health services. Barriers identified included negative staff attitudes/behaviour, lack of reasonable adjustments, communication problems, lack of knowledge of services, eligibility issues, lack of support of carers and language issues.

3. Azmi 1997	Community: North West England	Explored accommodation, individual support, day services, service support, social and recreational activities, friendships and relationships, ethnic and racial identity and racism and stigma in South Asian adolescents and adults with LD	Content-analysis of semi-structured interviews	People with a learning disability aged 14 or over identified from a total population survey of people with LD from South Asian communities.	21	Pakistani: 62% Gujrati: 19% Bengali: 14% Indian: 4.7%	14-44, median = 22	57%	Content of interviews	South Asian participants had a strong and positive sense of their racial and ethnic identity and generally satisfied with their home and family circumstances. However, they experience racism and stigma throughout all areas of their lives. They experience a lack of culturally appropriate services, limited friendships and closer relationships and a lack of meaningful leisure activities.

4. Bhaumik 2011	Service transition, social care, mental health care: Leicestershire and Rutland	Quantified the number of teenagers with a learning disability, their needs and carers' perceptions of transitions between services	Postal survey and interviews, mixed methods	Carers of teenagers with a learning disability between the ages of 16 and 19	79 postal question-naire, 24 interviews	Caucasian: 56 South Asian: 17 African heritage: 4 Mixed: 1 Other: 1	16-19	60.8%	Reported needs, carers' perception of service transition and unmet needs	Most teenagers had a significant level of learning disability, multiple problems and needed constant supervision. Most teenagers were involved with a range of services, but carers reported unmet needs and difficulty accessing services. Ethnic groups showed differences in patterns of service use and unmet needs. Carers wanted more information and planning around transition.

5. Bhardwaj 2017	Community: London and Kent	Described social network composition and barriers to social inclusion for people with a learning disability from South Asian and White communities	Behavioural measures and interviews, mixed methods design	People with a learning disability from South Asian and White backgrounds	47	White: 25 South Asian: 22 (individuals from Indian, Pakistani and Bangladeshi background)	19-60	57%	Network size and composition through behavioural measures and interviews	The average network size was 32 members. Differences by ethnicity were found, South Asian participants had more family members in their network while White participants had more service users and staff. South Asian group had a more mixed ethnic network while 96% of network members from the White participants were also White.
6. Bonell 2011	Specialist hospitals: three London boroughs	Explored family views on long-term out of area hospital care focusing on culture	Thematic analysis of interviews with carers	Carers of people with a learning disability in out of area inpatient hospitals	16	White British: 43.8% Bangladeshi: 25% Black Caribbean: 12.5% Other White: 6.3% Mixed White/Black Caribbean: 6.3% Pakistani 6.3%	Ns, mean = 35 (SD 11)	87.5%	Themes identified through interviews with carers	Identified theme of 'choice and culture'. Cultural needs were often met, such as attending services, but there were examples of cultural needs not being met and concerns about lack of contact with culture while in hospital. Although distance to the units was important as were cultural issues, families were mostly concerned about the quality of care and services.

7. Caton 2007	Health, social and care services: North West region	Responsiveness and appropriateness of services as reported by service providers	Thematic analysis of open-ended questionnaires	Service commissioners, service providers and other service provision organisations	18	ns	ns	ns	Themes identified through open-ended questions	Legislation and guidelines were used to help services develop guidelines. Organisational culture impacts on how services respond. Individual staff members and good organisational support facilitate effective policies, practices and procedures. Funding is cited as a barrier. Core theme of marginalisation of the issue of meeting needs of people from ethnic minority groups.

8. Chinn 2011	Psychiatric hospitals: 3 London boroughs	Explored views of people placed in out of area inpatient psychiatric hospitals	Consultation with service users through interviews and thematic analysis	People with a learning disability who were inpatient at specialist psychiatric hospitals	17	White British: 50% Other ethnic minority communi-ties: 50% (no breakdown)	Ns, mean = 34	76.5%	Themes identified through thematic analysis of semi-structured interviews	Within the themes identified there were issues around limited opportunities for service users to maintain their cultural and religious practices and keep in touch with their religious identities due to limited interaction with others from their home community. Participants felt group-based treatment meant their cultural and religious identities were lost.
9. Craig 2006	Community, secondary care: London	Explored discourses of parents relating to gastronomy tube feeding and disabled children	Interviews with mothers and discourse analysis	Mothers of children with disabilities who were tube fed	22	White: 68% Black African: 14% Black Caribbean: 4.5% Chinese: 4.5% Pakistani: 4.5% Other: 4.5%	29 to 49	0%	Discourse analysis of interviews	Normalisation discourse is referred to throughout mothers' accounts, viewing their children as not 'normal' and speaking about stigma. Feeding practices are presented as coercive conflict with normative expectations of 'good mothering' and the 'idealised autonomous child'.

10. Croot 2012a	Community: ns	Described coping strategies of Pakistani parents caring for a child with severe learning disabilities	Interviews with Pakistani parents of children with severe learning disabilities	Pakistani parents of children with severe learning disabilities	12	Pakistani: 100%	Disabled children: 4 to 16 years	33%	Coping strategies identified by constant comparative coding of interviews	Coping strategies included sharing care with others, using external support and recognising and enjoying the rewards of caregiving. Coping strategies are not specific to the Pakistani population, but some aspects of them may be different to parents with different heritages.
11. Croot 2012b	Community, physiotherapy services: Northern city in the UK	Identified factors Pakistani parents of children with learning disabilities felt were important components of care whilst considering cultural competence	Interviews with parents and thematic analysis	Pakistani parents and one grandparent of children with a learning disability	12	Pakistani: 100%	Disabled children: 4 to 16 years	33%	Themes generated through analysis of in-depth interviews	Concept of cultural competence may be of limited use when it depends on concepts of ethnic groups as fixed with clearly defined sets of health beliefs and behaviours - nothing to suggest areas of care important to Pakistani parents were different to those of the majority population.

12. Dobson 2002	Community: West Yorkshire	Investigated views, attitudes, awareness of autism, knowledge of services and priority of need of Asian carers of people with autism	Semi-structured interviews with carers and vignettes, mixed methods	Carers whose first language is Urdu/ Punjabi, Bengali or Gujarati who care for someone with autism spectrum disorder	36 (12 in each 3 groups)	Asian (native speakers of Urdu/ Punjabi/ Bengali or Gujarati)	ns	ns	Themes identified by analysis of interviews	Linguistic groups showed similar information needs between Asian communities. Participants showed varied knowledge of autism with some confusion about how it relates to other illnesses, uncertainty about its cause and religious attributions about its cause and course.

13. Durling 2018	Community: Tower Hamlets	Explored parenting with an intellectual disability in a Bangladeshi community in London	Interviews with parents who have a learning disability	Bangladeshi parents with a learning disability, family members and community members	6 members of the Bang-ladeshi community, 4 Bangla-deshi parents with a learning disability and 4 of their family members	Bangladeshi: 100%	Parents: 21-50, family member: 21-40, community members: 21-50	29%	Themes identified through analysis of interviews	'Intellectual disability' is not a concept that is shared by or easily explained to the Bangladeshi community. Within the community, people are expected to join the 'cycle of life' which includes marrying and having children and allows people with ID to access these roles. Marrying and becoming a parent is viewed as a way to secure long term care for the person with a disability. Parenting in the community is seen as a constellation of shared tasks not as one role.

14. Hatton 2010	Community: North West	Compared perceptions and impact of challenging behaviour in families caring for someone with a learning disability of majority and minority communities	Semi-structured interviews with carers, interpretative phenome-nological analysis.	Carers in 7 majority and 7 ethnic minority families (5 Muslim, 1 Hindu, 1 Christian)	14	White: 50% Ethnic minority groups: 50% (6 interviewed in Gujrati and 1 Urdu/ Punjabi)	Majority group: 36-53, Minority group: 33-70	ns	Interpretative phenomeno-logical analysis of semi structured interviews	There was not a linear relationship between the difficulties experienced by the person with ID and negative impact - aspects of human capital, social capital and socio-economic position were much more relevant to how families manage behavioural difficulties. Families from ethnic minority communities were more likely to report negative experiences.
15. Heer 2015	Community: West Midlands	Explored cultural differences in caregiving in South Asian parents	Interviews with South Asian parents of a child with a learning disability, interpretive phenome-nological analysis.	South Asian parents with a child with a learning disability.	7	South Asian: 100% (India, Pakistan) Muslim, Sikh)	27-42	29%	Interpretive phenome-nological analysis of interviews	Findings suggest South Asian parents adopted Western perspectives while trying to incorporate traditional Asian cultural beliefs which sometimes led to conflict and confusion. Parents struggled to cope with caregiving and managing everyday life stressors.

16. Heer 2016	Specialist services: England	Explored the experiences of service providers from a range of professions working with South Asian families	Focus groups with service providers, used interpretive phenome-nological analysis.	Service providers recruited from localities with high numbers of South Asian population; from NHS as well as private and voluntary organisations offering peripatetic and domiciliary support to people with LD.	20	White British, Scottish or European: 70% British Indian: 15% British Pakistani: 10% African Caribbean: 5%	ns	30%	Interpretive phenome-nological analysis of interviews	Two superordinate themes emerged: language as a primary barrier to therapeutic engagement and understanding and managing cultural difference.
17. Hersov 2007	Community: Greater London	Explored the importance of spiritual, religious and/or cultural life for Jewish people with a learning disability and their families	Interviews and discussion groups with people of Jewish heritage with a learning disability and their families	Jewish adults with a learning disability and parents of Jewish adults with a learning disability	17 adults with a learning disability, 18 parents	ns Jewish faith	ns	20s-70s	Interpretation of interviews	People with a learning disability felt being Jewish was an important part of their identity, providing a sense of strength, social belonging and inclusion. A significant number of participants wanted more opportunities to develop their spirituality and culture. Parents wanted designated people at their synagogue whose role was to promote inclusion of their child and more sensitive and timely support from professionals.

18. Chauhan 2012	Primary care: North West	Looked at the clinical impact of annual health checks and service user experience of health checks	Consultations with service users through interviews, analysis of primary health data, mixed methods	People with a learning disability, healthcare professionals, family carers and support workers	32 people with a learning disability, 40 health profession-als	People with a learning disability: White British: 21 Asian/Asian British: 6 Black British: 5	People with a learning disability: 24-70	People with a learning disability: 40.6%	Obstacles identified through analysis of interviews	The findings identified several obstacles affecting delivery of health care to patients with learning disabilities particularly in relation to access and communication, irrespective of whether they had a health check or not.
19. Hubert 2006	Community: London	Explored family carers views on the services received and needed and the cultural and communication barriers faced in accessing services	Interviews with family carers of ethnic minority background	Family members and carers of people with a learning disability from minority communities	30	Majority of families originated from the Caribbean and India	45-86	63%	Themes identified through grounded theory analysis of interviews	Carers in this population faced many problems that are common to all carers. Some issues affect ethnic minority groups in particular lar, such as communication (linguistic and cultural). Families raised many issues around access, service provision, accessible information, social isolation and service charges and reported high stress levels.

20. Kramer-Roy 2012	Community: United Kingdom	Explored the support needs of Pakistani families with disabled children in the UK	Participatory action interviews with family carers of people with a learning disability	Family carers of people with a learning disability from Pakistani communities	6 families	Pakistani: 100%	20	ns	Themes identified through participatory action interviews	Men noted there were negative attitudes towards disabled children in the community. Women appreciated opportunity to meet each other and tried to set up a support group, children of the families had never been asked about their experience living with a disabled sibling and wanted to understand their sibling better to 'make them happier'.
21. Larkin 2018	Community, social care: West Midlands	Explored the relationship to social care of people from an ethnic minority background with a learning disability	Interviews with adults with a learning disability, thematic analysis	Adults with a learning disability from ethnic minority communities	29 in final sample	Black Caribbean: 30% Pakistani: 25% remainder Indian, Bangladeshi or Mixed/ other	ns	ns	Themes identified through analysis of interviews	Participants were positive about services and evaluated these in terms of their relationships with the people providing support. Three distinctive narratives about independence were described - stability, progress and resistance. Participants used cultural resources and identities better than may be expected.

22. Malik 2017	Social care services: West Midlands	Explored meaning of social care services in the lives of British South Asian women with a learning disability	Interviews of British South Asian women with a learning disability Used a culturagram (family, religion, language, diet, leisure and festivities)	Adult British South Asian women with a learning disability	10	British South Asian: 100% (India, Pakistan or Bangladeshi Heritage)	Adults over 18 (women)	0	Themes identified through Interpretative phenome-nological analysis of interviews	Three themes were generated focusing on how services facilitate the development of complex identities, how the participants felt 'stuck' between cultures and the triple disadvantage of the intersection between gender, ethnicity and disability. Participants were broadly satisfied with the role services played finding them valuable and helpful.
23. McCarthy 2021	Community: England	Explored South Asian carers' perspectives on forced marriage of people with a learning disability	Interviews and focus groups with South Asian carers of people with a learning disability	South Asian carers of people with a learning disability	22	South Asian: 100%	ns	10%	Themes identified through thematic analysis of focus groups and interviews	A key motivator in forced marriage for adults with a learning disability is securing long-term care. There was awareness that forced marriage for people with LD could have highly negative outcomes. There was only limited awareness and understanding of the laws prohibiting forced marriage and less of constructs of capacity and consent.

24. McClimens 2013	Community: South Yorkshire	Explored the views on cultural needs of Pakistani family members of someone with a learning disability for a patient simulator	Focus groups with family members of a person with a learning disability	Pakistani family members of a person with a learning disability	8	Pakistani origin, Asian British	ns	12.5%	Findings described through focus group findings	Focus group discussions reinforced the need to be clear about heterogeneity within ethnic groups, although participants all had origins in the Kashmir region of Pakistan, there are different strands of Islam and different ethnic groups within regions.
25. Munroe 2016	Mental health services: UK	Investigated the experience of African immigrant mothers living in the UK with a child diagnosed with autism spectrum disorder	Interviews with mothers of children with autism spectrum disorder and a 'learning disability'	African immigrant mothers of children with an autism spectrum disorder	6	Mothers were from Sierra Leone (n = 1), Ethiopia (n = 1), Nigeria (n = 2) and Uganda (n = 2)	30-45	0%	Interpretive phenome-nological analysis of semi-structured interviews	Many aspects of the mothers' experiences related to their position as immigrants from cultures with contrasting belief systems regarding child development and disability. Mothers felt cognitive dissonance between African cultural beliefs and western views of ASD.

26. Raghavan 2007	Community: Bradford	Mapped service access and utilisation and described barriers to service access	Semi-structured questionnaire and interviews of young people with a learning disability and their family carers, mixed methods	South Asian young people with a learning disability and their family carers	35 young people with a learning disability	Pakistani: 89% Bangladeshi: 11%	14-25	72.3%	Service use and themes identified through inter-views	Most accessed primary care through GPs, had contact with social services for support and benefits and the voluntary sector for culturally appropriate services. Most participants did not access mental health services or professionals such as psychologists and specialist nurses. Families reported key barriers such as lack of awareness of services, language difficulties and lack of culturally sensitive services.
27. Russ 2021	Community, secondary care: London, UK	Evaluated service users from BAME and LGBT+ groups and/ or a learning disability's perceptions of an app designed for safer surgical care	Focus groups with people from BAME or LGBT+ communities	People who were from BAME or LGBT+ backgrounds or had a learning disability who have had surgery in the last 5 years or were awaiting upcoming surgery	22 – 50% from BAME back-grounds and 59% with a learning disability	White: 50% Asian/Asian British: 14% Black/ African/ Caribbean/ Black British: 23% Mixed/ multiple ethnic groups: 14%	18-24: 1 25-34: 2 35-44: 2 45-54: 4 55-65: 9 >65: 3	54%	Themes identified through analysis of focus group discussions	Strong degree of support for the app, most agreed it was acceptable in terms of content and useability. Specific user groups were identified as having barriers accessing the app such as those with visual impairments or a learning disability.

28. Sandhu 2017	Community: UK	Explored narratives by Turkish speaking families about migrating to the UK with a family member with learning disability	Interviews with families, narrative analysis	People with a learning disability and their families who were Turkish speaking and had migrated to the UK	5 families, 23 partici-pants	Kurdish: 3 families Cypriot: 2 families	People with a learning disability: 10 - 39	ns	Themes identified through narrative analysis of interviews	Seeking help for the person with learning disability was central to narratives. Family member with a learning disability was described as caught up with geopolitical conflicts. Families faced challenges within their own communities and accessing local services.

29. Sham 1996	Community: Greater Manchester	Explored the culture, religion, attitudes and backgrounds of Chinese minority groups living in Britain with a child with a learning disability	Formal and informal interviews of Chinese families with a family member with a learning disability	Families with a child who has a learning disability who were of Chinese origin	6 families	Chinese – Cantonese speaking, all families came originally from Hong Kong, 5 from the New Territories	Family members with a learning disability: 11-20	Family members with a learning disability: 66.6%	Themes identified through case studies	Language barriers were a problem and interpreting issues about health and illness can lead to long-term misunderstanding and inappropriate action by parents (e.g. turning down respite care believing this would involve the child being taken away). Chinese families have belief systems that need to be understood by services, families may be identifying causes and potential cures for disability. Offence can be caused when beliefs aren't understood (e.g. a social worker caused offence by attending a New Year celebration wearing white, leading a family to fear bad fortune).

30. Terashima 2011	Health and social service providers: West London, East London, South of England	Explored the issue of cultural diversity amongst service users with a learning disability and the barriers of their access to direct payment supports	Interviews with service providers, phenomenological analysis	Service providers, professionals from health and social care and voluntary services who provide provision for people with learning disabilities	24 service providers, professionals from health and social care and the voluntary sector	Focus on provision to South Asian communities	ns	ns	Experiences described through phenomenological analysis of interviews	Cultural bias in services can leave those from South Asian communities feeling alienated and reluctant to access services. Services might be refused if they were not sensitive to lifestyle differences. Language barriers can prevent access to services and welfare entitlements.
31. Tuffrey-Wijne 2017	Residential/ supported living services: London	Investigated the factors that affect the communication of death-related bad news to people with a learning disability	Semi-structured interviews, thematic analysis	Staff members working at 8 different intellectual disability supported living or residential services in London	20	Country/Area of origin: Eastern Europe: 6 African: 6 UK:4 Southern Europe: 1, Rep. Ireland: 1 Caribbean: 1 South America: 1	26-40: 6, 41-60: 12, 60+: 2	15%	Themes identified in analysis of semi-structured interviews	Staff found supporting people with a learning disability around death and dying extremely difficult and avoided communication about death. Factors influencing practice included: fear and distress around death, life and work experience and organisational culture. Staff attitude toward bad news disclosure included the influence of staff cultural background.

Table F: Quantitative papers included in the review.

First Author and Year	Setting	Focus	Design	Key sample features	Sample size	Ethnic categories used for analysis	Age range	% male	Relevant out-come measures	Key findings
32. Ainsworth 2001	Secondary care: Birmingham, West Yorkshire, Bristol	Described cases of Micro syndrome in Muslim Pakistani children	Retrospective case series of 11 cases of children from a Pakistani background with Micro syndrome	Children attending one of five British hospitals, all of Pakistani origin	14	Pakistani	1-15	42.9%	Description of findings from case histories	Discussion surrounding early diagnosis, for families and medical professionals to be aware of low-level vision. With advice of genetic counselling being offered to wider family due to the high rate of consanguinity.

33. Beer 2005	Mental health services: South London, Kent, Surrey, Sussex	Described characteristics of patients exhibiting severe challenging behaviour in low secure mental health and mild learning disability units	Audit survey of patients being treated in low secure units, descriptive statistics	Patients being treated at low secure units, 70% mental health units and 30% learning disabilities units	200	Mental health patients: White: 53% Black Caribbean and African: 12% Other: 5% Learning disabilities patients: White: 23% Black Caribbean and African: 10% Other: 3.5%	19 to 74, mean = 39	77%	Character-istics and number of patients in the Black, Caribbean or African group	Those in mental health units were more likely to be diagnosed with schizophrenia and had greater number of hospital admissions. In learning disability units patients were more likely to be Black, Caribbean or African, have higher risk to self and others and have a diagnosis of autism or mild LD. For a third of patients standard 5 of the National Service frameworks was not met because they were not in the 'least restrictive environment'.
34. Bhaumik 2008	Mental health services: Leicestershire and Rutland	Investigated characteristics of individuals with a learning disability seen by psychiatric services and the nature and prevalence of psychiatric disorders	Analysis of cross-sectional data of psychiatric service attendance, prevalence rates	Adults with a learning disability using specialist services in Leicestershire and Rutland between 2001 and 2006	1244 seen by psychiatric services	White: 88% South Asian: 9% Other/ unknown: 4%	19 – 29: 20.4% 30-39: 23.8% 40-49: 23.4% 50-59: 19.1% 60+: 13.3%	56.8%	Accessed specialist learning disability services at least once during the study period	Of the adults with LD, 45.9% accessed specialist psychiatric services at least once during the study period. Those attending psychiatric services were more likely to be older and to live in residential settings and less likely to be South Asian or have mild/ moderate ID.

35. Bone 2014	Secondary care: England	Explored inequalities in the experiences of care by patients with cancer	Secondary analysis of cross-sectional data by Quality Health of patients whose primary diagnosis was of cancer	Patients with a primary diagnosis of cancer who attended an NHS hospital as an inpatient or day case	71,793	White: 88.7% Mixed: 0.3% Asian/Asian British: 1.5% Black/Black British: 1.2% Chinese: 0.2% Other: 0.7%	16-25: 0.5% 26-35: 1.4% 36-50: 9.5% 51-65: 31.9% 66-75: 32.9% 76+: 23.9%	47.1%	Analysis of survey responses of patients rating of their care quality	Female, non-white and younger patients were less likely to rate their overall care as excellent or very good. Patients with long-standing conditions, particularly those with learning disability or mental health problems, also reported poorer care.
36.Bonell 2012	Specialist hospitals: three London boroughs	Described the experience of people with a mild learning disability of mental health inpatient services	Two round Delphi process: n = 36 in round 1, n = 24 in round 2, questionnaires and interviews	People with mild learning disability using specialist inpatient mental health services	24	Black British, Black African or Black Caribbean: 54.2% White British: 45.8%	White: 36-65 Black: 21-51	54.2%	Median response, level of agreement	The Black group were less positive about a range of experiences, suggesting they have a more varied experience of services and were more dissatisfied by staff not speaking their home language and use of medication. There was less agreement in the Black group than the White group (agreement reached for 5 items vs 20 items). Consensus on positive experiences of services was reached in the White group but not for the Black participants.

37. Bouras 2003	Mental health services: London	Measured the number of referrals to specialist mental health services to identify trends	Retrospective analysis of referrals over three time periods: 1983-88 when first long-stay institution in the area closed, 1989-94 when the second institution closed and 1995-2001 when there were no local long-stay institutions	First time referrals to a specialist mental health service for people with a learning disability and psychiatric disorder	752	White: 77.9% Afro-Caribbe-an:15% Asian: 4% Other non-white: 3.1%	<24: 33.1% 25-54: 26.6% 35-44: 20.5% 45-54: 11.7% 55 plus: 8.1%	60.6%	Number of referrals by ethnic group	Increased referrals by ethnicity over the three time bands. Marked increase in the number of referrals of those of African/Caribbean origin which increased from 7.7% in the first band to 18.7% in the third time band. Referrals for Asian groups increased from 2.3% to 5.2% and 1.5% to 4% for other non-White groups.

38. Carey 2021	Primary care: England	Calculated risk factors for excess all-cause mortality during the first wave of COVID-19	Retrospective cohort study of primary care records which partitions all-cause mortality during the first wave of COVID-19 in 2020 into two components: “usual” (non-excess) mortality, estimated from age-adjusted mortality in the same season in five pre-pandemic years; and “excess” mortality	Data from 770 practices of patients who were active in similar time periods in 2015-2020. Analysis of first-wave of the pandemic was 18th March to 19th May 2020. Data was restricted to adults between 30 and 104 years.	Study population 4.8 million in 2020	ns	Patient records of those between 30-104 years	ns	Risk factors of excess mortality in those from ethnic minority backgrounds and those with a learning disability	Being of non-white ethnicity was associated with one of the greatest risk factors of excess mortality (black vs. White EMR = 2.50, 95% CI 1.97 - 3.18; compared to UMR = 0.92, 95% CI 0.85 - 1.00), as was having a learning disability (EMR 8.54, 95% CI 5.99–12.18 compared to UMR = 3.64, 95% CI 3.29 - 4.04).

39. Chadwick 2005	Mental health: England	Follow up study reassessing children with a learning disability in adolescence for behaviour problems and psychiatric diagnoses	5 year follow up of a community sample, re-assessments of sample for behaviour problems, psychiatric diagnoses, severity of LD and puberty status through structured interviews	Sample of children with severe intellectual disability identified from registers of 6 special schools. Children first identified in 1996-1997 when they were 4-11 years old and reassessed in 2002-2003 at 11-17 years old	82	96.3% of children born in the UK 50% of children were from ethnic minority backgrounds	11-17, mean = 13.06	56.1%	Differences between initial and follow up ratings of severity of behaviour problems	The prevalence of mental health and behavioural problems in young people with severe learning disabilities remains relatively stable between childhood and adolescence. Rates of some problems including overactivity showed significant reductions between time points. Persistence rates for most behaviour problems were similar to the general population.

40. Chaplin 2017	Prisons: England	Identified and described male prisoners with a learning disability compared to prisons without a learning disability	Cross sectional design, screening of prisoners using interviews and standardised assessment to describe their demographics, comorbidities, and presence of learning disability or mental health problems	Sample of male prisoners, participants with learning disability were defined as those who scored <46% on the Learning Disability Screening Questionnaire. Mental health data was compared between LD and non-LD prisoners	240	No neurodevelopmental disorder: White: 44% Black and ethnic minority: 56% Learning disability: White: 78% Black and ethnic minority: 22%	No neurodevelopmental disorder: 20-35: 57.5% 36+: 42.5% Learning disability: 20-35: 94% 36+: 6%	100%	Prevalence of prisoners with a learning disability, characteristics of those with a learning disability compared to prisoners who screened negatively	18 prisoners identified as having a learning disability. Those with a learning disability were less likely to be from an ethnic minority background, be over 35 or have any qualifications. They were more likely to have been single, homeless or unemployed before coming into prison. Prisoners with LD were significantly more likely to have mental health problems and 25% had thought about suicide in the last month. 63% had attempted suicide in the past. Prisoners with LD were more likely to be housed in the vulnerable prisoners' wing and significantly more likely to have committed robbery than other prisoners.

41. Chaplin 1996	Mental health services: Leicester	Described patterns of psychiatric outpatient service use of Asian adults with learning disabilities	Retrospective analysis of case notes for year 1991. South Asian participants matched with two White controls.	South Asian and White outpatients with a learning disability seen by service in one hospital	114	South Asian: 33.3% White Caucasian (matched controls): 66.7%	South Asian: mean = 30.2 (SD 7.5) White Caucasian: mean = 29.8 (SD 7.8)	63%	Psychiatric diagnoses, number of contacts with service, source of referral	Asian adults with a learning disability were significantly underrepresented with respect to the local population (measured by the learning disability register) but not the population of individuals with LD known to the psychiatric services. South Asians were significantly more likely to receive a psychiatric diagnosis, in particular that of psychosis, but there were striking similarities between the South Asian group and controls in the routes of referral, the number of contacts with the service and the range of defined disabilities.

42.Chen 2020	Mental health services: Cambridge and Peterborough	Quantified medium-term impact of the first COVID-19 lockdown on the rate of referrals to secondary mental health services	Controlled interrupted time series design using clinical health records of Cambridge and Peterborough NHS foundation trust. All records from 2020-01-01 to 2020-03-15 were used as pre-lockdown period and records from 2020-03-23 to 2020-05-19 as the post-lockdown period. Records from the same time periods in 2019 were included as a control year.	Patient information during routine treatment from records, including age, gender, ethnicity, marital status, referral time, referral destination, diagnoses and medication data	Records from NHS trust serving around 0.86 million	ns	ns	ns	Referral rate and acceleration in those from ethnic minority backgrounds and those with a learning disability	Lockdown resulted in instant drop in mental health referrals but a longer-term acceleration in referral rate. No significant post lockdown acceleration was observed in those of ethnic minority backgrounds or those with intellectual disability.

43. Chitsabesan 2006	Prisons, community: England and Wales	Survey of young offenders measuring their level of medical health need in the community and in secure care	Describes needs in mental health, education/ work and social/ relationships of young offenders in the community and in secure units, screens young offenders for presence of LD and psychiatric disorders	Cross sectional survey of young offenders in 6 geographically representative areas across England and Wales	301	White British: 83% African-Caribbean: 9% Asian: 2% Mixed race: 5% Other:<1%)	13-18, mean = 15.7 (SD 1.3)	77%	Number of young offenders screened to have a learning disability, differences in needs across ethnic groups	One in five young offenders was identified as having a learning disability (IQ<70). Young offenders from ethnic minority backgrounds had more post-traumatic stress symptoms and less educational needs but small numbers in ethnic minority groups precluded further analysis.

44. Cummins 2021	Primary and secondary care: London	Explored the factors related to COVID-19 hospitalisations, critical care admissions and mortality	Cohort study of service use and mortality outcome using Secondary Uses Service hospital inpatient data creating risk of hospitalisation, ICU admission and death following admission due to COVID-19, risk factors	People who tested positive for COVID-19 between 2020-02-01 and 2020-06-30 in the NEL areas of City of London and Hackney, Newham and Tower Hamlets	1781	White: 35.1% Asian: 34% Black: 23.9% Mixed: 1.9% Other: 4.5% Not known or Not stated: 0.6%	16-49: 31.6% 50-69: 35.8% 70+: 32.6%	55.2%	Risk of hospitalisation, ICU admission and death for those of an ethnic minority and those with a learning disability	Compared to people of White ethnicity, people of Black ethnicity were at higher risk of hospitalisation (OR = 1.54, CI [1.13, 2.09], p = .006). People of Asian ethnicity were at 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). People with a learning disability had the greatest risk of death associated with a single clinical factor.

45. Curtis 2022	Primary care: England	Studied trends in vaccine uptake and characteristics of vaccine recipients	Retrospective cohort study on 57.9 million patient records from general practice in England	Cohort of all patients registered with a general practice in England beginning on 2020-12-08 at the start of the national vaccination campaign and ending on 2021-03-17. Patients with unknown date of birth or unknown sex were excluded.	57.9 million records, 20, 852, 692 patients receiving a vaccine	ns	ns	ns	Vaccine uptake by ethnicity and learning disability	There was substantial variation by ethnicity in patients receiving a vaccine in priority group 2 (>80 years and not in a care home) - White: 96.2% vs Black 68.3%. Patients with pre-existing medical conditions were more likely to be vaccinated but learning disability was an exception to this with a lower uptake rate (91.4%).

46. Das-Munshi 2021	Mental health services: London	Assesses standardised mortality ratios in people with mental disorders and learning disabilities to compare risks of death before and during the COVID-19 pandemic	Analysis of prospective data from a large mental healthcare provider in London to assess the excess risk of mortality across nine condition (schizophrenia-spectrum disorders, affective disorders, somatoform/neurotic disorders, personality disorders, learning disabilities, eating disorders, substance use disorders, pervasive developmental disorders and dementia)	Health records from South London & Mawdsley NHS Foundation Trust, cohorts created of people with defined and intellectual disability diagnoses followed from date of diagnosis until death or the end of the study. All people entering the cohort were alive on 2019-01-19 and followed until death or 2020-12-31. 167,122	167,122	White British: 45% Irish: 1.9% Black Caribbean: 11.6% Black African: 5.9% South Asian: 2.6%	ns, mean age = 44	48%	Age and gender standardised mortality ratios (SMRS) for those with learning disabilities and by ethnicity	By the second quarter of 2020 COVID-19 SMRs elevated across all conditions, learning disabilities 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.

47. Davis 1991	Community: East London	Evaluated a home-based intervention of family-focussed counselling	Standardised assessments and questionnaires were used to evaluate the intervention, participants were randomly allocated to intervention or control groups	Participants from English-speaking and Bangladeshi families (mothers) of children with intellectual or multiple disabilities, most of lower socio-economic groups. Bangladeshi children were almost all moderately to severely developmentally delayed with multiple disabilities, most children in the English speaking group were globally delayed	Bangladeshi families: 16 in parent advisor group, 12 in control group English-speaking families: 31 in parent advisor group, 21 in control group	Bangladeshi: 28 English-speaking (not specified further): 52	Bangladeshi families: Parent advisor group: maternal age = 21-47, child age (months) = 18-185 Control group: maternal age = 24-54, child age = 17-166 English-speaking families: Parent advisor group: maternal age = 20-50, child age = 6-142 Control group: maternal age = 24-42, child age = 8-117	Child sex M:F ratio: Bangladeshi, parent advisor group = 10:6, control group = 6:6 English-speaking, parent advisor group = 21:10, control group = 15:6	Degree of improvement seen in intervention vs control groups through a general family counselling style intervention	Benefits of a family-focussed counselling intervention were most evident in Bangladeshi families where the intervention group showed changes not seen in controls: mothers came to see themselves as better supported, families felt under less stress and mothers became more positive about their families and themselves. Bangladeshi children in the intervention group improved significantly y in developmental progress. Benefits were seen for the intervention group in English-speaking families but they were not as marked as those for the Bangladeshi group.

48. Devapriam 2008	Community: Leicester and Rutland	Compared carer profiles, stress levels and level of unmet needs and psychological symptoms in those from White and South Asian backgrounds	Retrospective cross-sectional study using intellectual disability register records	Carers of adults with a learning disability on LIDR living with family carers (mainly parents)	742	White: 63% South Asian: 37%	Carer age: South Asian = >65: 14% White = >65 Person with a learning disability: South Asian = <35:69% 35-49: 26% 50+:6% White = <35:62% 35-49: 30% 50+: 9%	Carer sex: South Asian = 15% male White = 18% male Person with a learning disability: South Asian = 59% male White = 58% male	Differences in stress levels of carers and level of unmet service needs between groups	Carers of South Asian adults with a learning disability reported significantly higher levels of care provision and unmet needs than carers of White adults. In unadjusted analysis carers of South Asian adults had higher stress levels than carers of white adults.
49. Doshi 2009	Community: London Borough of Tower Hamlets	Investigated oral health, oral health awareness and oral health behaviours in Bangladeshi young adults with a learning disability	Convenience sample of people attending a day centre who took part in structured interviews and oral examinations	Bangladeshi service users attending a day centre in Tower Hamlets, 84% graded as having a moderate learning disability, 15% mild learning disability	52	Bangladeshi: 100%	20-39, mean = 28	42%	Reports of oral health behaviours and oral health awareness and oral health outcomes	Oral health behaviours were generally unfavourable and participants had generally poor oral hygiene. Women were more likely to express dental anxiety than men and had a preference for seeing a female dentist from their own background. Periodontal treatment was required for 88% of participants from the oral examination.

50. Dunkley 2017	Community, primary care: Leicestershire and Rutland	Screening study of people with a learning disability for type 2 diabetes to determine the prevalence of previously undiagnosed type 2 diabetes and glucose intolerance	Cross-sectional population-based screening between 2012-12 and 2015-09, logistic regression used to assess associations	Sample of adults with a learning disability who did not have a previous diagnosis of diabetes or a systemic disease that may interfere with measurement of glycated haemoglobin, recruited through general practice registers, learning disability register, specialist LD psychiatric service clinics or direct contact through publicity	930	White: 80.4% Asian: 15.8% Black: 1.5% Mixed: 1.4% Other: 0.9%	Mean = 43.4 (SD 14.2)	57.7%	Rates of undiagnosed diabetes and impaired glucose regulation and differences by ethnicity	Diabetes status was successfully assessed for 73% of participants. 1.3% were found to have undiagnosed type 2 diabetes and 5.2% were found to have impaired glucose regulation. Participants of non-white ethnicity were almost four times more likely than white participants to have abnormal glucose levels.

51. Durà-Vilà 2009	Mental health services, social services, community: London	Examined ethnic cultural group differences in service utilisation among children with intellectual disabilities	Service evaluation and audit data from schools and administration staff using case files. Used binary logistic regression to identify variables that predict service uptake	Children in 4 special schools, mostly with moderate intellectual disabilities, living with families	242	White British: 31% South Asian: 15% Black group: 20% Middle East/ Arab: 14% White European: 9% Mixed/other: 11%	7 – 17, 67.3% within age range 13-17 years	67.3%	Service utilisation	CAMHS services uptake was lower for South Asians than for White British. Statistically significant differences among ethnic groups for community based social services uptake (highest for Black groups and lowest for South Asians) and respite care uptake (highest for Black and lowest for South Asians). Family structure predicted CAMHS service utilisation and social service community support and ethnicity predicted use of respite care.

52. Ellis 2008	Community: Greater London, West Midlands and the South West of England	Assessed factors associated with granting of the Disability Living Allowance (DLA) for Down syndrome	Cross-sectional survey, logistic regression models used to assess characteristics associated with granting of DLA	Cohort of families who participated in a community-based randomised control trial of vitamin supplementation between 2002-05 and 2004-02. Families with children with severe inoperable congenital cardiac defects and life-threatening long-term illness were excluded as were families who spoke no English	156, 138 completed follow-up	White: 80% Ethnic minority: 20%	In follow up sample: 18.6-35.9 months, mean = 22.9 months	59%	Survey responses about outcome of DLA application and socio economic and developmental factors	Application for DLA was not associated with ethnicity. Significantly fewer ethnic minority patients (OR = 0.10; 95% CI 0.04 to 0.62; 67% vs 93% risk difference 26%) and patients with English as an additional language (OR = 0.15; 95% CI 0.04 to 0.62; 67% to 93% risk difference 23%) were granted the DLA.

53. Emerson 2012	Community: England	Estimated the association between household disadvantage, local area deprivation, ethnicity and the identification of intellectual and developmental disability	Cross-sectional survey, multilevel multivariate analyses of educational record data on household disadvantage, local area deprivation, ethnicity and identified developmental disability	Data extracted from the English Spring 2008 School Census from 7-15 years of age, included children being educated at home, at state schools and at independent schools	5.18 million	White British: 78.2% Pakistani: 3.1% Other White Back-ground: 3.1% African: 2.5% Indian: 2.3% Caribbean: 1.4% Bangla-deshi:1.3%) White and Black Caribbean: 1.2%) Other Mixed Back-ground:1.2% Other Asian Background: 1.1% Other Back-ground: 1.1% White and Asian: 0.7% Other Black Background: 0.5% Irish: 0.4% Chi-nese: 0.4% White and Black African: 0.3% Gypsy/ Romany: 0.1% Traveller of Irish heritage: 0.1%	7-15	ns	Level of household disadvan-tage, local area deprivation, ethnicity and disability	Lower household socioeconomic position was associated with increased rates of identification of ID and DD especially less severe forms of ID. Higher area deprivation was independently associated with increased rates of identification of less severe forms of ID but decreased rates of identification of profound ID and ASD. Ethnic minority status was associated with lower levels of identification of ID and DD with exceptions of the Gypsy/Romany and Traveller children, and higher rates of identification of severe forms of ID were found in children of Pakistani and Bangladeshi heritage.

54. Emerson 1997	Community: North of England	Estimated prevalence of severe learning disabilities in British Asians compared to non-Asians	Reports results of one of two projects, one looking at service use among Asian children and adults with learning disability and another predicting future demand for housing support, used prevalence rates	Sample from 3 metropolitan boroughs in the North of England. Sample were Asian people identified as having a learning disability through multiple sources, including contacting child health services, educational services, specialised learning disabilities, etc	148 Asian children and adults identified through 2 boroughs for project 1, 73 identified through 1 borough for project 2	Asian: 100%	0-45+	ns	Prevalence of severe learning disabilities	Below school age (0-4) there is little difference in the prevalence of severe learning disabilities between Asian and non-Asian communities. Between 5 and 34 years of age the apparent prevalence of severe learning disabilities is approximately three times higher in the Asian community compared to non-Asian communities.
55. Emerson 2004	Community: inner city in England	Identified factors associated with levels of psychological distress experienced by family carers of children with a learning disability	Cross-sectional survey via postal questionnaire (or interview where English was not first language) from family carers about demographics, severity of developmental delay and additional impairments	Sample from administrative area marked by significant levels of social deprivation, drawn from Local Education Authority database that recorded the primary special educational needs of all school-age children	1,319 in total sample identified through database, 408 responses to questionnaire	White: 70% South-Asian: 18% Black: 7% Other: 6%	5-16	63%	Stress levels in carers, effect of socio economic deprivation on stress	47% of primary carers scored above the threshold for psychological distress. Scoring above the threshold was strongly related to the emotional and behavioural needs of the child they were caring for and South-Asian ethnicity. It was also moderately associated with the child's delay in communication.

56. Emerson 2005	Community: Birmingham	Emotional and behavioural needs of children with a learning disability	Cross-sectional survey via postal questionnaire (or interview where English was not first language) from family carers. Information on mental health needs of children collected from child's teacher (for a 50% random sample of children) and family carers, used odds ratios	Sample from administrative area marked by significant levels of social deprivation, drawn from Local Education Authority database that recorded the primary special educational needs of all school-age children	615	White: 74% South Asian: 14% Black: 7% Other: 5%	5-16	65%	Developmen-tal Behaviour Checklist and teacher version scores, odds ratio	48% of children scored above the 'caseness' threshold on the DBC, this was associated with white ethnicity (OR 2.2 [95% CI ns, p = 0.005]). Ethnicity was associated with special educational needs category with a notably high proportion of South Asian children categorised as being SLD (48% compared with 28% among other ethnic groups). Disruptive/antisocial subscale of DBC-T was associated with not belonging to South Asian ethnic group.

57. Emerson 2007	Community: Birmingham	Emotional and behavioural needs of Black and Asian children with a learning disability and social deprivation	Cross-sectional survey of teacher-reported emotional and behavioural needs assessed using Nisonger Child Behavior Rating Form and the Adaptive Behavior Scale – School version. Deprivation measured by linking households to the Index of Multiple Deprivation (IMD), regression modelling used, scores on N-CBRF dependent variable	Sample from administrative area marked by significant levels of social deprivation, drawn from Local Education Authority database that recorded the primary special educational needs of all school-age children	909	South Asian: 69% (Bangladeshi, Indian, Kashmiri, Sikh, Gujarati, Mixed South Asian) Black: 17% (Black Caribbean, Black African, Black other, Black British, Mixed black heritage) Mixed: 8%	South Asian: mean = 13.6 (ns) Black: mean = 12.6 (ns)	South Asian: 61% Black: 69%	Scores on the N-CBRF and IMD	Teachers reported higher rates of emotional and behavioural needs in Black children compared to South Asian children. Older children, children of lower ability, children without sensory impairments and male gender were associated with higher rates of emotional and behavioural needs. For Black children increased deprivation was associated with increased need, but for South Asian children increased deprivation was associated with decreased need.

58. Hatton 1998	Community: two boroughs in North West England	Explored family circumstance, service support and carer stress of carers of people with a learning disability in South Asian communities	Question-naires and interviews with carers, thematic analysis	South Asian carers of people with a learning disability	54	Pakistani (34), Bangladeshi (9), east African Asian (9), Indian (2)	22-68 (mean 45)	3.7%	Stress levels, material disadvantage and themes identified through interviews	High levels of stress, material disadvantage and service need were identified. Awareness and uptake of specialist learning disability services was low. Low service uptake and satisfaction levels were due to a lack of information, lack of staff with language skills, and neglect of cultural needs.

59. Hatton 2009	Community: Northern England	Investigated how socioeconomic position moderates the impact of child behaviour problems on maternal mental health in South Asian families with a child with a learning disability	Part of a larger mixed methods study, cross-sectional survey design using structured interviews with South Asian family carers, univariate analyses and logistic regression	Sample of family carers of children identified as 'severe learning disabilities' by education systems or 'severe learning difficulties' from five local education authority areas in Northern England	123	Pakistani: 70.7% Indian: 17.9% Bangladeshi: 9.8% East African Asian: 1.6% Muslim: 93.5% Hindu: 4.1% Sikh: 2.4%	22-63, mean = 39 (ns)	Parents: 0% (all mothers) Children with LD: 1-21 (mean = 11.3, ns)	Child behaviour problems and maternal distress, relationship with socio-economic deprivation	Parents reported higher levels of child problem behaviour if they scored above thresholds for anxiety and distress and rated themselves as in fair/poor/very poor health. Regressions suggested a moderating effect of socioeconomic position and on the relationship between child problem behaviours and parental anxiety, depression and self-reported poor health. However, socioeconomic position did not moderate the association between child behaviour problems and maternal distress.

60. Hatton 2021	Community, primary care: UK	Investigated willingness of people with a learning disability to take COVID-19 vaccines	Cross-sectional cohort study using structured interviews and surveys with people with LD and carers, analysis used statistical significance tests of associations between variables	Two samples, adults with LD and family carers or support workers (where adult with LD would not be able to take part in an interview)	621 adults with LD, 348 family carers or support workers	Adults with LD: White: 94.7% Other ethnic group: 5.3% Carers: White: 94.1% Other ethnic group: 5.9%	Adults with LD: 16-44 – 68.2% 45+ - 11.2% Carers: 16-44 – 80.8% 45+ 18.3%	Adults with LD: 51.3% Carers: 56.5%	Willingness to take COVID-19 vaccine and factors associated with this	87% of participants with a learning disability were willing to take a COVID-19 vaccine. Willingness to take the vaccine was associated with white ethnicity, already having had a flu vaccine, gaining information about COVID-19 from television but not from social media, and knowing COVID-19 social restriction rules. 81.7% of surveyed carers reported that the person with LD would be willing to take a COVID-19 vaccine.

61. Johnson 2015	Secondary care: East Midlands	Assessed neuro developmental outcomes in infants born late and moderately preterm	Prospective, population-based study which uses parent questionnaires at 2 years of age to assess neurosensory impairments and the Parent Report of Children's Abilities-Revised to identify cognitive impairments. Relative risks for adverse outcomes were adjusted for sex, socio economic status and small for gestational age, and weighted to account for over-sampling of term-born multiples. Risk factors for cognitive impairment explored using multivariate analyses.	Families in the sample had children born late-to-moderately preterm (between 32 and 36 weeks), recruited at birth. Control group was parents of term-born babies.	Preterm group: 638 Term-born group: 765	Preterm group mothers: White: 78.5% Mixed: 2.0% Asian or Asian British: 14.7% Black or Black British: 3.6% Chinese or other: 1.0% Unknown: 0.2% Term mothers: White: 82.5% Mixed: 1.0% Asian or Asian British: 11.2% Black or Black British: 4.4% Chinese or other: 1.0%	Preterm group mothers: <20 years: 3.2% 20-24 years: 14.7% 25-29 years: 29.9% 30-34 years: 32.8% >35 years: 19.5% Term mothers: <20 years: 2.3% 20-24 years: 13.9% 25-29 years: 26.2% 30-34 years: 30.3% >35 years: 27.3%	Parents: 0% Preterm infants: 53.8% Term infants: 50.2%	Risk factors for cognitive impairment	Preterm infants had a higher rate of neurosensory impairment than term controls (1.6% vs 0.3%, RR 4.89, 95% CI 1.07 to 22.25). Cognitive impairments were the most common adverse outcome: LMPT 6.3%; controls 2.4% (RR 2.09, 95% CI1.19 to 3.64). MPT infants were at twice the risk for neurodevelopmental disability (RR 2.19, 95% CI 1.27to 3.75). Non-white ethnicity was an independent risk factor for cognitive impairment in preterm infants.

62. Joy 2020	Primary care: England	Described mortality in England and its association with known or likely COVID-19 cases, demographic and risk factors	Cross-sectional analyses of people with known COVID-19 status in the Oxford RCGP Research and Surveillance Centre (RSC). Used survival modelling and probability analysis.	Clinical data uploaded from volunteer general practice members from all patients registered at general practices in the RCP netowrk on 2020-05-11 and having >1 year of health records in the network.	56, 658	White: 67.1% Asian: 6.1% Black: 2.6% Mixed, other: 2.2% Missing: 22%	<65: 69.8% 65-74: 11.3% >75: 18.9%	40%	Risk of death in those of ethnic minority backgrounds and those with a learning disability	Compared with white ethnicity, Black ethnicity was associated with increased mortality (OR = 1.84, 95%CI= 1.33 to 2.54,P = 0.0002). Socioeconomic status did not change association of mortality. People with learning disabilities had a higher odds of mortality OR = 1.97, 95%CI= 1.22 to 3.18, P= 0.0056).
63. Kerr 2001	Learning disability services: Manchester	Described social and functional characteristics of young people with a learning disability and additional needs	Cross-sectional study with cohort of children to assess prevalence of the case definition of learning disability with additional severe disabilities (SLD-AD)	Young people with severe learning disability who also had additional severe disabilities (SLD-AD) of secondary school age in the 1998-9 cohort of Manchester young people of compulsory secondary school age	57 included in additional analyses	South Asian: 22% Black or mixed black/ white: 2%	12-16	55%	Prevalence of severe learning disability in those from ethnic minority backgrounds	Prevalence of severe disability was markedly higher among young people of South Asian background.

64. Kiani 2013	Community, learning disability services: Leicestershire and Rutland	Compared prevalence of mental illness, autism spectrum and behaviour disorder in people with a learning disability living in urban and rural areas	Cross-sectional study using the Leicestershire Intellectual Disability Scale and postcode data. Analysed using chi-square tests.	Adults (19+) with a learning disability registered with the learning disability service in Leicestershire between 2001-01-01 and 2006-12-31. Those with borderline intellectual functioning (performing above threshold on LIDR) and with a missing postcode address were excluded. Separates sample into those living in urban and those living in rural areas.	2,713 total Urban: 1,507 Rural: 1,2066	Urban: White: 75.3% South Asian: 21% Other/ unknown: 3.7% Rural: White: 95% South Asian: 2.7% Other/ unknown: 2.3%	Urban: <30: 28.9% 30-39:23.6% 40-49: 20.8% 50+: 26.7% Rural: <30: 27.9% 30-39: 23.6% 40-49: 22% 50+: 26.5%	Urban: 57.5% Rural: 54.8%	Prevalence rates of mental illness, autism spectrum and behaviour disorder, variation by area and ethnicity	More people from an ethnic minority were living in urban areas than rural areas. The prevalence of mental illness was lower in the ethnic minority population than in the white population (21.4% vs 35.4%)

65. Kroll 2002	Forensic: England	Assessed mental health, social and educational needs of boys in secure care for serious or persistent offending	Prospective longitudinal design using standardised interviews and psychometric tests, participants assessed at two time points three months apart	Adolescents who were on long term placements (>3 months), measured needs and psychiatric morbidity before they entered secure care and 3 months after their placement	97 at time 1 90 at time 2	White: 80% African-Caribbean: 3% Asian: 2% Mixed: 10% Other: 4%	Mean: 14.9 (SD 1.0)	100%	Rates of psychiatric, social and educational needs	27% of the boys had an IQ of less than 70. There was a high level of psychiatric problems on admission, the most frequent disorders were depression and anxiety. High rates of aggression, substance misuse, self-harm and social, family and educational problems and associated needs. The mean difference in needs between admission and 3 months post admission was 5.6 (95% CI 5.0 - 6.3).

66. Leese 2006	Mental health services, forensic: England	Describes socio-demographic, clinical and offence profiles of patients in high-security psychiatric hospitals by ethnic group	Cross-sectional analysis of characteristics of patients using standardised interviews and case notes, analysis with chi-squared tests and t-tests	Sample of groups of patients during the period 1999-2000 including women detained under all legal classifications, men detained under the legal classification of mental impairment, mental illness, dual legal classification or psychotic disorder. Patients on trial leave were excluded.	1,081	White: 81% Black: 19%	White: mean = 40.03 (SD 10.66) Black: mean = 38.35 (SD 8.89	White: 83% Black: 89%	Rates of admission, mental illness, personality disorder and learning disability	Black patients in high security psychiatric hospitals were overrepresented 8.2 times (range 3.2 - 24.4, 95% CI 7.1-9.3), are more often male and more often diagnosed with a mental illness and less often diagnosed with a learning disability than white patients. Black patients had significantly more unmet needs than white patients (mean values of 2.22 v 2.62, 95% CI 0.06-0.73).

67. L'Esperance 2021	Primary care: England	Determined the range of directed enhanced services (DES) in primary care and equity of service provision	Cross-sectional analysis of general practice data in England from 2018-2019, used multiple linear regression modelling	Sample was all general practices in England (n= 6,873). Practices were excluded if they had negative funding amounts or <750 registered patients.	6,849	ns	0-65+	ns	Levels of DES provision	Mean DES funding was £6.25 per patient, this was £0.35 lower in deprived areas (95% CI = £0.60 to £0.10). Ethnic group related differences were not significant. In deprived communities there was less immunisation activity and provision of extended hours access but there was greater learning disability checks provision.
68. Linehan 2002	Mental health services, forensic: Ireland	Determine d the representation of Irish Travellers among transfers from prison to psychiatric hospital	Cross-sectional analysis of admissions to hospital and committals to prisons between 1997-1999, interviews for health screening, admission rates	Sample of admissions to psychiatric hospital and committals to prisons of patients of White European, black and other ethnic minority groups and Irish Travellers	Admissions to CMH: 484 Admissions to prison: 224	Admissions to CMH: White European: 92% Black & ethnic minority: 2% Irish Traveller: 6% Committals to prison: White European: 89% Black & ethnic minority: 6% Irish Travellers: 5%	ns	ns	Admission rates	Irish Travellers accounted for 3.4% of forensic psychiatric admissions compared to 0.38% from the adult population. More learning disability and less severe mental illness were found among travellers transferred from prison to psychiatric hospital than other groups. Black and other ethnic minorities had a higher proportion of severe mental illness.

69. Liverpool 2021	Mental health services: England	Explored shared decision making (SDM) reported by parent/ carers and associations between SDM and clinicians' perceptions of children's difficulties	Secondary analysis of administrative data from CAMHS between 2011 and 2015, analysis using multilevel modelling	Sample of those accessing the Children and Young People's Improving Access to Psychological Therapies between 2011 and 2015, cases from 58 services	3,175	White: 68% Mixed race: 6% Asian: 7% Black: 5% Other: 14%	0 to 10: 41% 11 to <25: 59%	48%	Associations between demographic factors and SDM variables	In the first model there were statistically significant associations suggesting Asian parents/carers (OR = 1.95, 95% CI [1.4, 2.73]) and parents/ carers having children with learning difficulties (OR = 1.45, 95% CI [1.06, 1.97]) were more likely to report higher levels of SDM.
70. Maitland 2006	Mental health services: South East London	Investigated the source of referral to specialist mental health service for people with intellectual disabilities	Retrospective study of new referrals, binary logistic regression performed with source of referral as independent variable	Sample of new referrals to a specialist mental health service for people with intellecutal disabilities	791	White: 77% Black: 15% Other non-White: 8%	16-86, mean = 33.5 (SD 13.5)	61%	Source of referral	People referred from GMHS were more likely to be from the Other non-White (predominantly Asian) ethnic group (11.0%) than those referred from PC/SS (6.1%) ($\chi 2 = 6.19$, df = 1, p = 0.01), and people referred from PC/SS were more likely to be White (79.5%) than those referred from GMHS (72.9%) ($\chi 2 = 4.52$, df = 1, p = 0.03). In regression model, the Other non-White group were more likely to be referred from GMHS (OR 1.76 (1.01–3.06)).

71. Marr 2001	Secondary care: Birmingham	Described high myopia in early childhood and its associations with systemic and ocular problems	Retrospective case review from medical records using descriptive statistics and chi-squared tests	Sample of children who were found to have myopia of 6 dioptres spherical equivalent or more in one or both eyes before the age of 10 years presenting to Birmingham Heartlands Hospital and Birmingham Children's Hospital between 1995 and 1998	112	Caucasian: 58% Chinese: 2% Afro-Caribbean: 2% Asian: 38%	3 days to 9 years 11 months, mean = 2.5 (SD 2.5)	66%	Associations of myopia and systemic and ocular problems	Asian and male patients were overrepresented. 8% of the children had 'simple high myopia', 54% had an underlying systemic association (e.g. developmental delay, Down syndrome) and 38% had further ocular problems.

72. Masefield 2021	Primary care: Bradford	Explored association between caregiving for preschool children with developmental disabilities and maternal health and healthcare using cohort data	Secondary analysis cohort study using linked primary care and Born in Bradford (BiB birth cohort data, analysis with regression models	Sample of paired mothers and children from the BiB cohort who had electronic primary care records available from 12 months before and 5 years after the index child's birth, a BiB baseline questionnaire, linked primary care records available for the index child from ages 0-5, children who survived beyond the age of five, one child per mother (or first born child).	477 caregivers of preschool disabled children 7,250 other mothers	Caregivers of disabled children: White British: 40.6% Other: 11.7% Pakistani: 47.8% Other mothers: White British: 40.3% Other: 15.8% Pakistani: 43.7% Missing: 0.2%	Caregivers of disabled children: 15-49, mean = 27.6 (SD 6.9) Other mothers: 15-44, mean = 27.9 (5.6)	0%	Associations between mothers' healthcare use and symptoms between groups	Mothers of disabled children had higher levels of psychological distress than other mothers (odds ratio 1.24; 95% CI 1.01, 1.53) but did not access health services more and were less likely to access healthcare services for psychological distress (0.64; 0.40, 1.02).

73. McGrother 2002	Community, specialist services: Leicestershire	Compared prevalence rates of intellectual disability, morbidity and service need among South Asian and White adults	Cross-sectional analysis of structured home interviews, chi-square test and logistic regression used.	Sample of all South Asian and white adults known to the Leicestershire Learning Disability Register in 1991.	2,540	South Asian: 8% White: 92%	South Asian: mean = 33.7 (ns) White: mean = 41.2 (ns)	South Asian: Male: female ratio = 1.64 White: Male: female ratio = 1.31	Associations between prevalence rates, morbidity and service need between groups	Prevalence rates of learning disability in adults in Leicestershire were 3.20 per 1000 in South Asians and 3.62 per 1000 in whites. South Asian adults with LD have similar prevalence of disabilities and significantly lower skill levels. South Asians show similar levels of psychological morbidity but make significantly lower use than whites of psychiatric services, residential care and respite care. There were no differences in community service use but South Asians feel they have a greater unmet need.

74. Morris 2021	Mental health services: England and Wales	Investigated ethnic differences in Mental Health Act (MHA) sections and the factors associated with this	Retrospec-tive review of case notes of consecutive admissions between 2014-02 and 2020-01 to a secure forensic CAMHS developmen-tal disorder inpatient unit, analysis using relative risk, odds ratio, Fisher's exact test and t-tests	Convenience sample of admissions detained under the MHA who had developmental disorder and mental health needs. Participants had been detained at a 40 bed Tier 4 service consisting of two medium secure male wards, one male low secure ward and one female low secure ward. 34 participants drawn from previous study (Morris et al. 2020).	39	Ethnic minority: 30.8% White British: 69.2%	minority: mean = 16.83 (SD 1.27) White British: mean = 17.19, (SD 1.44	Ethnic minority: 91.7% White British: 70.4%	Factors associated with MHA detainment	Adolescents from ethnic minority backgrounds were at 5 times greater risk of being detained on forensic sections of the MHA than their White British counterparts. There were no significant differences between ethnic minority and White British participants on demographic variables, clinical needs, risk behaviours, risk measures, application of restrictive practices or safeguarding procedures.

75. Morton 2002	Secondary care: Derbyshire	Reported prevalence of severe Neurodisability in children from different ethnic groups	Cross-sectional analysis of healthcare records, analysis uses prevalence rates	Sample of records of children attending a child development centre for severe disability and children on the local special needs database with severe disability, up to 19 years of age, separated by ethnicity	837	Indian: 2% Pakistani: 6% Mixed group (of which 95% Caucasian indigenous, Black Caribbean, Black African, Chinese, Bengali): 91%	Up to 19 years	ns	Mean disability scores, prevalence rates	Pakistani children had higher prevalence rates of severe learning disorder, severe and profound hearing loss and severe visual problems, and a slightly increased rate of autism and cerebral palsy. Pakistani groups showed a lower prevalence of language disorder. Disability scores for Pakistani attending the Child Development Centre were higher than for other groups. Genetic disease causing disability was 10 times more common in the Pakistani children than other groups.

76. O'Hara 2003	Community: Tower Hamlets	Investigated areas of service provision and deficiencies and outcomes between two cultural groups of parents with learning disabilities	Retrospective survey of semi-structured interviews and case notes, analysis using descriptive statistics	Parents with a learning disability who were identified through community teams for people with learning disabilities who had contact between January 1995 – 2000.	52	English: 42% Bangladeshi: 58%	English males: 25-32 English females: 29-68 Bang-ladeshi males: 21-47 Bang-ladeshi females: 21-36	36.5%	Morbidity, degree of learning disability and charac-teristics of parents with a learning disability	The four subgroups had similarly high rates of specialist psychiatric referral (over 70%). English women were referred for symptoms of psychiatric illness or concerns about adequacy of parenting, whereas Bangladeshi women were referred because of symptoms suggestive of a psychiatric illness or episodes of aggression. Parents with a learning disability tend not to receive needed support, services are patchy and constrained by resources.

77. Parrott 2008	Community: Sheffield	Described the changes in the population of people with a learning disability in Sheffield and associated demand for services	Cohort study, analysis of assessments for complex needs, used prevalence rates	Sample from the Sheffield Case Register of people who met the WHO definition of profound and multiple learning disabilities between the ages of 14 and 19, excluding those who have severe and complex needs such as autism	40 with PMLD	PMLD: 37.5% from Black and minority ethnic communities, 17.5% of these from the Pakistani community	14-19	ns	Prevalence of LD, models predicting change over time	The number of people with LD in Sheffield increased by 25% between 1998 and 2008. The number of people with LD from BME communities increased by 80% between 1998 and 2008.
78. Parry 2021	Community: West Midlands	Evaluated a youth development program for improving resilience and wellbeing and whether young people differed in outcomes according to demographics	Intervention study using sport psychology program designed to aid young people in their ability to recognise and use their mental skills to improve self-regulation, used standardised measures of outcomes, analysis using MANOVA and ANOVA	Sample of young people who had experienced homelessness or were at risk of becoming homeless within a housing service, 28 of 246 had a learning disability	246	White: 56.1% Black/African/ Caribbean/ Black British: 22% Mixed/ multiple ethnic groups: 16.3% Asian or Asian British: 3.3% Missing 2.4%	16-25 years	38.2%	Correlations between variables	There were significant baseline differences in resilience according to ethnicity and learning difficulty. Those of a Black ethnicity reported higher baseline resilience than those of white ethnicity. There was a significant improvement in resilience and well-being over time which was associated with mental skills development.

79. Raghavan 2009	Community: Bradford	Investigated the effectiveness of a liaison worker in helping young people and their families access appropriate intellectual disability services	Non-blinded randomised control trial to evaluate the effectiveness of a specialist liaison service over 9 months. Treatment group had access to a liaison worker helping them get in touch with and take up appropriate services.	13-25 year olds with intellectual disabilities screened for mental health problems, participants were eligible if they tested positive for mental health problems/ challenging behaviour and were receiving services for these problems	26, 12 treatment, 14 control	Pakistani: 88.5% Bangladeshi: 11.5%	13-25	ns	Number of services contact, number of outcomes from contacts	Participants allocated the specialist liaison worker has statistically significantly more frequent contact with services and with more outcomes than the control groups, and significantly lower scores on the Strengths and Difficulties Questionnaire.

80. Ruane 2019	Mental health services: Dublin	Examined the effectiveness of a parenting training programme for parents of children with developmental disabilities	Non-blinded randomised control trial, treatment group received Group Stepping Stones Triple P (GSSTP) parenting program and waiting list controls (WLC). Parents assessed with standardised measures of child behaviour at three time points before during and after the treatment.	Sample recruited from clinical psychology services. Parents of children with a range of developmental disabilities and co-occurring internalising and externalising behavioural difficulties.	84, 44 in GSSTP group and 40 in control group	GSSTP: Irish: 88.6% African: 6.8% Other: 4.5% WLC: Irish: 85% Polish: 2.5% African: 2.5% Asian: 5% Other: 5%	Child's age: GSSTP group: mean = 5.45 (SD 2.06) WLC group: mean = 6.01 (SD 2.01)	4.7%	Clinical improvement and change rates	After the programme clinical improvement and reliable change rates of children's behaviour and difficulties were significantly higher for those in the GSSTP group than controls.

81. Sturmey 2009	Mental health care: England	Investigated the use of restraint, seclusion and PRN medication in services for people with learning disabilities	Secondary analysis of audit data from the Healthcare Commission, uses incident rates and proportions	Health Care Commission survey of people with an intellectual disability, 88.7% living in NHS settings and 14.5% living in independent sector units. 1,223 were detained under the Mental Health Act.	3,904	White: 91.9% Mixed: 1.5% Asian or Asian British: 3.2% Black or Black British: 2.8% Chinese or Other Ethnic group: 0.3% Not known: 0.4%	ns	ns	Incident rates and proportions	Around 80% of service units reported using PRN medication and half of service units used restraints. The most commonly reported form of restraint was physical restraint. The range of proportions indicated that a minority of service users experienced restrictive procedures many times more than the mean (e.g. physical restraints mean 0.81, median 0.0, range 0.00-45.00).

82. Tsakanikos 2010	Mental health services: South East London boroughs (Lambeth, Lewisham and Southwark)	Investigated the role of ethnicity in clinical psycho-pathology and care pathways	Retrospective study of new referrals, used binary logistic regression with ethnicity as dependent variable	Sample of new referrals to specialist mental health service for adults with LD	806	White: 76.8% Black: 15.4% Other: 7.8%	16-86, mean = 33.6 (SD 13.6)	60%	Clinical diagnoses and care pathways	Lower proportion of White participants referred from mainstream mental health services ($\chi 2$ = 4.04, df = 1, p = 0.04). Between group differences for schizophrenia spectrum disorders (White: 15.5%, Black: 23.4%, Other non-White: 28.6%; $\chi 2$ = 9.89, df = 2, p = 0.007) and dementia (White: 4.2%, Black: 0.8%, Other non-White: 0.0%; $\chi 2$ = 6.04, df = 2, p = 0.05). Schizophrenia spectrum disorder less likely to be found in White participants in comparison to other ethnic groups (OR 0.46 (95% CI 0.31–0.77)), and more likely in the Black group than the other ethnic groups (OR 1.70 (95% CI 1.01–2.76)). Schizophrenia spectrum disorder was more likely in the Other non-White group (OR 2.21 (95% CI 1.22–4.01)).

83. Tyrer 2006	Community: Leicestershire and Rutland	Investigated the prevalence of physical aggression towards others in adults with a learning disability	Cross-sectional analysis of interview data, reports prevalence rates and uses multivariate modelling with aggression as the dependent variable.	Sample of carers of adults on the Leicestershire Learning Disability Register, interviewed between 1993-01-01 and 2004-12-31	3,062	White: 86% South Asian: 11% Other/ unknown: 3%	<20: 8% 20-29: 21% 30-39: 23% 40-49: 21% 50-59: 14% 60-69: 8% >70: 5%	57%	Prevalence of physical aggression, association between physical aggression and other factors	14% of adults were physically aggressive towards others. Ethnicity was not associated with aggression. There was a significantly higher prevalence of aggression in men, younger people and those in institutional settings. People with Down syndrome had lower prevalence of physical aggression. Failing to cope among carers was reported by 42% of those caring for adults with aggression, compared to 10% without aggression.

84. Tyrer 2007	Community: Leicestershire and Rutland	Investigated the impact of physical, intellectual and social impairments on survival	Cross-sectional analysis of interviews, survival analysis using Cox proportional hazards models	Sample of data from the Leicestershire Learning Disability Register of interviews with carers and adults >20 with a learning disability	2,453	White: 83% South Asian: 15% Other/ unknown: 4%	>20	57%	Hazard ratios of risk of death	Of the adults in the sample, 16% died over a maximum follow-up period of 19 years. Physical impairment was the only impairment to significantly predict survival. Being non-mobile was associated with 7x greater risk of death (adjusted hazards ratios (HR) ¼ 7.14; 95% confidence interval (CI) 4.99–10.21).

85. Tyrer 2019	Community, primary care: Leicestershire	Investigated the prevalence of multimorbidity and associated risk factors	Cross-sectional analysis using data from a diabetes screening cohort, analysed using multiple logistic regression with multimorbidity as the dependent variable	Sample of adults aged 18-74 who were involved in the 'STOP Diabetes' screening cohort, recruited from GP and specialist LD services. Adults were excluded from the screening if they had existing diabetes, life limiting terminal illness or systemic disease interfering with the measurement of glycated haemoglobin.	920	White: 82.2% South Asian: 15.3% Black African/ Caribbean: 1.4% Mixed: 1.3% Other: 0.8%	18-74, mean = 42.9 (SD ns)	57.6%	Prevalence of multimorbidity, factors associated with multimorbidity	The prevalence of multimorbidity was 61.2% (95% CI 57.7-64.7). Multimorbidity was independently associated with being female, and severe/profound LD Those who were sedentary or inactive were more likely to be multimorbid, after adjusting for ability to walk, age, gender, severity of LD, ethnicity and socio-economic status (adjusted OR = 1.91; 95% CI 1.23–2.97; P = 0.004 and OR = 1.98; 95% CI 1.42–2.77; P < 0.001).
86. Tyrer 2020	Community: Leicestershire and Rutland	Investigated prevalence of diabetes and associated factors	Cross-sectional secondary analysis of interview data, used logistic regression and prevalence rates, diabetes as dependent variable	Interviews of adults with learning disability between 2010-01-01 and 2016-12-31	1,091	White: 82.2% South Asian: 12.7% Other/ unknown: 5.0%	18-29: 56.9% 30-49: 25.9% 50+: 17.2%	58.3%	Factors associated with diabetes	The lifestyles of the study population were unhealthy, with lower activity levels and low consumption of fruit and vegetables. Prevalence of carer/self reported diabetes was 7.3% (95% CI 5.9-9.0). Diabetes was positively associated with South Asian ethnicity and older age groups.

87. Verity 2021	Secondary care: UK	Investigated cases of progressive intellectual and neurological deterioration	Prospective study of clinical surveillance questionnaires from BPSU, used lifetime risk by dividing the number of diagnosed cases by the number of total births during the diagnosis period	Clinical data of children who fit the case definition of PIND as reported by paediatricians	2,008	White: 58.2% Black: 1.9% Indian: 1.3% Pakistani: 17% Bangladeshi: 2.2% Chinese: 0.25% Other: 19%	<1: 40% 1-4: 41% 5-9: 13% 10-15: 6%	54%	Characteristics of confirmed cases of PIND	There were over 220 different diseases in the cases. Of diagnosed cases, the two largest ethnic groups were White (58.2%) and Pakistani (17%). Of the Pakistani group, 86% had consanguineous parents. There was considerable similarity in the patterns of disease found in White and Pakistani children, but there were no cases of Menkes disease in Pakistani children.
88. Winstone 2017	Secondary care: UK	Described cases of Niemann-Pick type C (NP-C)	Prospective cohort study of clinical surveillance questionnaires from BPSU, describes prevalence and diagnostic delay	Clinical cases of children who fit the case definition of NP-C as reported by paediatricians	53	White: 75% Pakistani: 15% Black: 4% Indian: 2% Other/not known: 4%	Median age at diagnosis: 6 (0.3-18) Median age at onset: 3.75 (0.1-15.5)	45%	Characteristics of cases of NP-C	Fifteen cases had a systemic presentation (neonatal jaundice and/or hepatosplenomegaly). Thirty-eight had neurological onset, most common presenting symptom was gait disturbance/ataxia (76%). Forty-nine cases eventually had neurological problems.

89. Wood 2005	Community, secondary care: UK and Ireland	Described perinatal factors associated with later morbidity among extremely preterm children	Epidemiolog-ical population-based cohort study, analysis using regression with outcome variables (cerebral palsy, severe motor disability Bayley scores) as dependent variable.	Cohort of babies born between 20 and 25+6 weeks gestational age over the 10 months beginning 1995-03. Assessment of neurological and developmental functioning took place at corrected age of 30 months.	283	ns	ns	ns	Risk factors associated with outcomes	Boys were more likely to have adverse outcomes. Adverse motor outcomes (cerebral palsy, disability or Bayley psychomotor development index) were associated with factors such as perinatal illness, ultrasound evidence of brain injury, and treatment (postnatal steroids). Mental development was associated with a broader range of factors including ethnic group.

Table G: LeDeR reports included in the review.

ID, First Author and Year	Focus	Design	Key sample features	Sample size (notifications)	Ethnic categories used for analysis	% male	Key findings
90. Heslop 2018	Reported on the lives and deaths of people with a learning disability (and autistic people as of 2021) in England	Mixed methods analysis of reviews of deaths of people with a learning disability, MCCD data, and qualitative analysis of learning points (2017), best practice and quality of care (2018 and 2019, 2020 and 2021), age standardised mortality rates of avoidable deaths (2019, 2020, 2021), ethnicity specific analysis (2020)	People with a learning disability in England who were reported to the LeDeR programme and have completed reviews of their death at the time of analysis. Autistic people are included in the 2022 report onwards.	1,311	White: 93% Asian: 4% Other: 4%	57%	Most people were of White ethnic group (93%), median age at death of people who died was 58, this was 41 for those with profound learning disability and 63 for those with mild learning disability. Less than half of deaths notified to LeDeR stated a cause of death. 31% of people with a recorded cause of death had an underlying disease of the respiratory system.
91. Heslop 2019				4,302	White British: 90% Asian: 4% Other: 6	58%	Most people were of White British ethnicity (90%). Median age at death was 59. Most frequent cause of death was diseases of the respiratory system.
92. Heslop 2020				7,145	White British: 90% Asian: 4% Other white ethnic groups: 2% Mixed: 2% Other ethnicities: 2%	58%	Most people were of White British ethnic group (90%). Median age at death was 61. Most frequent cause of death was diseases of the respiratory system. People with a learning disability died of an avoidable cause of death twice as frequently as the general population.

93. Heslop 2021				8,488	White British: 91% Asian/Asian British: 4% Black/African/ Caribbean/Black British: 2% Mixed/multiple ethnic groups: 1%	57%	Most people were of White British ethnic group (91%). Median age at death was 62. Analysis on deaths of people from minority ethnic group showed the disparity between deaths of males and females was greater in people from the Black ethnic group. Adults with the lowest median age at death were males of the Asian/ Asian British ethnic group with profound and multiple learning disability (median age 30 years), followed by those of the Black ethnic group (33 years).
94. White 2022				12,398	Asian or Asian British: 3% Black, Black British, Caribbean or African: 2% Mixed ethnic group 3% White: 91% Other: 1%	56%	Most people were of the white ethnic group (91%). Median age at death was 62. The most common cause of death was COVID-19. Excess deaths during 2021 compared to pre-pandemic years was double that of the general population. Half of deaths of people with a learning disability were deemed to be avoidable.

Table H: Studies reporting health outcomes.

Health outcome	Relevant studies (study number, outcome described, first author and year)
Specific genetic or acquired syndromes	32 (Micro syndrome; Ainsworth 2001) 71 (high myopia; Marr 2001) 88 (Nimann-Pick type C; Winstone 2017)
COVID-19	38 (mortality; Carey 2021), 44 (mortality; Cummins 2021), 62 (mortality; Joy 2020), 46 (mortality; Das-Munshi 2021), 93 (mortality, Heslop 2021), 94 (mortality, White 2022)
Oral health	49 (periodontal treatment; Doshi 2009)
Diabetes	50 (prevalence; Dunkley 2017), 86 (prevalence; Tyrer 2020)
Physical, sensory, global and neurodisabilities (in addition to intellectual)	61 (neurosensory and cognitive impairments; Johnson 2015) 75 (range of neurodisabilities; Morton 2002) 84 (physical disabilities; Tyrer 2007) 87 (PIND; Verity 2021) 89 (range of neurodisabilities; Wood, 2005)
Multimorbidity	85 (multimorbidity; Tyrer 2019), 91 (multimorbidity, Heslop 2019), 92 (multimorbidity, Heslop 2020), 93 (multimorbidity, Heslop 2021), 94 (multimorbidity, White 2022)
Mental health	33 (challenging behaviour; Beer 2005), 59 (behavioural problems; Hatton 2009), 39 (behavioural problems, psychiatric disorders; Chadwick 2005) 34 (psychiatric disorders; Bhaumik 2008), 64 (psychiatric disorders, autism; Kiani 2013), 65 (forensic/psychiatric problems; Kroll 2002), 66 (forensic/psychiatric problems; Leese 2006), 82 (psychiatric disorders; Tsakanitos 2010) 56 (emotional and behavioural needs; Emerson 2005), 57 (emotional and behavioural needs; Emerson 2007), 83 (physical aggression; Tyrer 2006) 74 (MHA detainment; Morris 2021)

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Appendix 4: Workshop Themes

Appendix 4A - Transitional Care for Adults

What is transitional care?

Transitional care for adults can include:

Moving between care settings, such as moving from hospital to home.

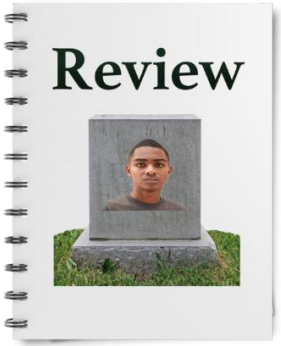
Having access to a new service.

Making sure that people have the support they need and that different health care teams talk to each other about the person's needs.

When we talk about access, we mean the right care, in the right place, by the right person, at the right time.

What does the research show?

Coming out of hospital



The LeDeR report found that some people were sent home before they were well enough.

Sometimes information about the person might not have been told to different health care teams who cared for the person.

Access to health services

Adults who normally see their GP don't know about other help that may be available.

If you need less help services may not be available to you.

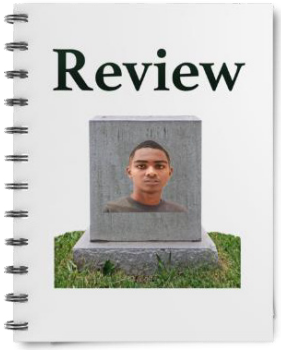
Our findings say that health staff need more training.

The research say that extra help should be closer to home.

Health care staff don't talk to each other about you and your needs

Appendix 4B - LeDeR

What is LeDeR?



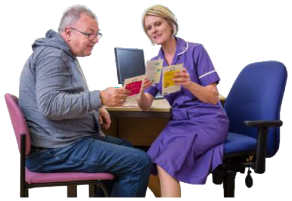
Learning from Lives and Deaths – people with a learning disability and autistic people (LeDeR) programme

They will talk to:

1. Health care professional
2. General Practice (GP)
3. Family member
4. Care provider

When someone with a learning disability over the age of 4 dies, their death can be told to LeDeR.

The aim of a LeDeR review is to look at the problems with the health and health care of the person that died.



A LeDeR review looks at the health and health care of the person who died.

This helps to make care better for people with a learning disability and stops people dying younger than they should.

What did the 2021 report show?

This year's report looked at the people who died in 2021.

1. Most people we heard about, who died, were white British.

2. BUT people from minority ethnic backgrounds were more likely to die younger.

This means that many white people with a learning disability lived longer than people that were black, Asian or from mixed backgrounds.

SO, LeDeR are not being told about all of the people who die with a learning disability from a minority ethnic background.

We need to learn more about the people from minority ethnic backgrounds who died.

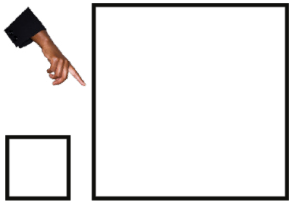
Appendix 4C - Transition

What do we mean by 'Transition'?

When people go from childhood to young adult

Care and treatment changes services between age 15-18

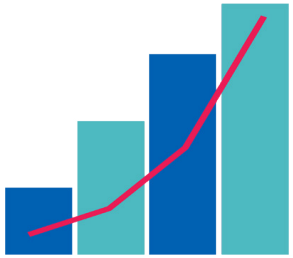
You will move from a children's hospital to an adult's hospital



There should be no gap in care and treatment

Everything should be planned with your carers to make sure there are no problems

What have we found



Teenagers need more care and treatment from their doctors and nurses during transition.

Teenagers from ethnic minorities use health services and leisure activities less than white teenagers.

Reasons could be down to what we believe in and our beliefs and traditions

Carers did not have knowledge of their teenager's transition

Not enough information about adult specialist services when transitioning.

Appendix 4D - Discrimination

What do we mean when we say discrimination?

‘Discrimination’ is when you are treated differently than others.

This could be because of your learning disability or because of your ethnicity.

We have found that people may be discriminated against because of both their learning disability and ethnicity.

We call this ‘double discrimination’.

What have we found?

We found that people and carers from ethnic minorities had more problems with accessing health care.

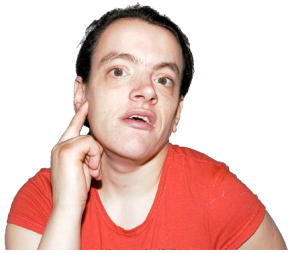
These problems were:

Health care professionals not understanding peoples beliefs, religion and how they live their life.

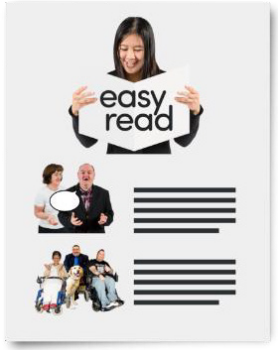
Carers did not know how they could get help and support.

Carers who did not speak English found problems getting the right care and treatment.

Many services did not provide a translator.



Not being listened to when talking to services.



Not enough easy read information.

Health care teams using words that people don't understand.

Appendix 4E - Digital Access

What do we mean when we say Digital access?

Being able to use computers and the telephone is really important.

Some people do not have access to these things.

Some people have never been shown how to use a computer.

Some people do not have the internet.

We call this Digital exclusion: not having access to a computer or smartphone or having poor internet access.

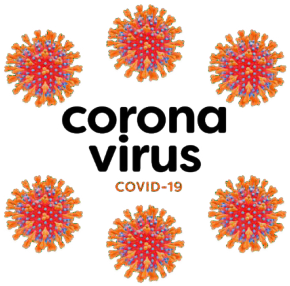
We would like to understand more about this.

The government's plan is to make access to healthcare easier in future.

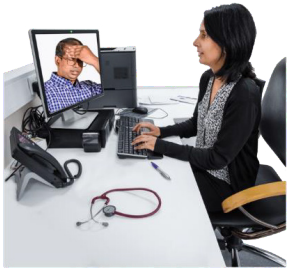
This includes access to your GP and health records.

On your health record it shows things like the medications you take and illnesses that you may have.

What have we found?



During the Covid-19 pandemic people with learning disability did not have the same access as other people to care and treatment.



We did not find information on how people with a learning disability from an ethnic minority used online GP services.

Appendix 4F - Community and Family Networks

What do we mean when we say ‘community’?

When we say the word ‘community’ we are talking about the people who are around you in your life.

This can be:

- Other people with learning disabilities
- Friends
- People using the same health and care services as you
- Your family
- The people from health and care services who try to help you

What have we found?

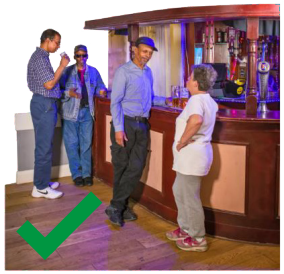
The research looks at people from South Asian backgrounds, such as people from Indian, Pakistani and Bangladeshi backgrounds.

We have found that people from a South Asian background have more people in their community and social networks than people who are White British.

We have found that people who are South Asian have a bigger family network.

White British people had more friends that they met in services and staff in their life.

People said they didn't have access to a lot of social activities.



People from an ethnic group would like to have access to social activities.

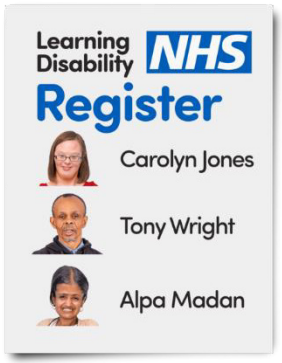
People from minority ethnic groups are more likely to live on their own or in their family home.

White British people are more likely to live in the community in supported living.

People from minority ethnic groups are more likely to get their main support from a family member or informal carer.

Appendix 4G - Learning Disability Register

What is the learning disability register?



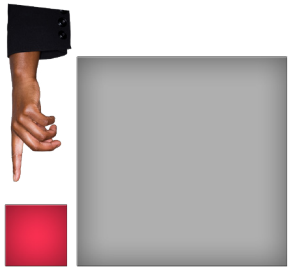
The learning disability register is a list of people who have learning disabilities.

Being on the learning disability register tells healthcare staff that they need to change their support and care to you and your situation.

The learning disability register also gives you priority for COVID vaccinations and helps you get a flu jab.

Doctors use it to make sure that people with learning disabilities get the right support in the right ways.

If you are over 14 and on the learning disability register you also get a free annual health check to make sure that you are fit and healthy, and that no problems or illnesses have been missed.



We think that only a small number of people (23%) with a learning disability are on the learning disability register.

People with learning disabilities don't always get the right help with their physical and mental health.

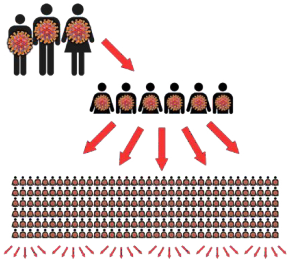
Appendix 4H - COVID-19

What have we found?

We found 9 papers that talked about COVID-19.

People from minority groups with a learning disability:

1. Were more likely to die from COVID
2. Are less willing to take up screening and vaccination programs such as the COVID vaccine



What do we know happened during the COVID-19 Pandemic?

People with a learning disability were six times more likely to die from COVID-19.

40% of the deaths were of people from Black and Pakistani communities.

White people who were in hospital for COVID-19 were happier than people from ethnic minorities about the care and treatment they had.

COVID-19 showed just how important the learning disability register is as people with a learning disability were not vaccinated.

COVID-19 has found that vaccination is lower across black, mixed, South Asian and other ethnic groups.

Early symptoms and warning signs were not noticed by staff.

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