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Coronavirus and People with Learning Disabilities Study

Wave 4: People from ethnic minority communities in England
September 2023

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Waves 1-3.
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Wave 4.
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Report Contents

1: Introduction

1.1. Background and rationale for this study

The Coronavirus and people with learning disabilities study has been tracking the experiences of people with learning disabilities across the UK through the COVID-19 pandemic[1]. The original study tracked the experiences of people at three time points (or Waves); December 2020 – February 2021; April – May 2021; and July – August 2021. At Wave 3, 489 adults with learning disabilities took part in online structured interviews, and a further 280 family carers or support workers of people with learning disabilities who could not take part in an interview provided information about the person they were caring for via an online structured survey.

At Wave 3, the ethnicity of only 22 people with learning disabilities in Cohort 1 (16 of whom lived in England) and 17 people with learning disabilities in Cohort 2 (8 of whom lived in England) was identified as being from ethnic groups other than White[2].

Wave 4 of the project was commissioned separately, after the end of the original project, with an additional wave of interviews and surveys starting in late summer 2022. The research team continued to examine the ongoing impact of the pandemic on the lives of people with learning disabilities in the UK, and began to look more broadly at the current living circumstances of people with learning disabilities in the UK in the context of economic difficulties and challenges for public services. Wave 4 also contained two additional elements, both focused in England, to attempt to address some of the limitations that had emerged from the experience of conducting the original project. The first of these was to conduct in-depth work with a small number of people and families to understand and share people's stories of their lives through the COVID-19 pandemic as a whole. The second additional element was to attempt to recruit 'booster samples' of 100 people with learning disabilities and 50 family carers/support workers of people with learning disabilities from ethnic minority communities, to allow for relatively detailed comparisons of people's circumstances and experiences across ethnic groups at Wave 4 of the study.

This report describes our attempts to recruit these booster samples to Wave 4 of the study, reflection on why we did not achieve our aims for this element of the study, some necessarily limited and broad-brush analyses of differences between people with learning disabilities from White British ethnic groups and people with learning disabilities from any other ethnic group, and some potential implications of this study for future research with people with learning disabilities from ethnic minority communities.

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[1] Findings from all waves of the study are available on the project website https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability/results/ (accessed 27 June 2023)

[2] In earlier waves of the study, we asked about relatively broad ethnic groups, so for Wave 3 'White' includes the ethnic groups of Irish, Gypsy or Irish Traveller, Roma, and Any other White background. For Wave 4, we used the more specific set of ethnic groups employed in the 2021 Census[2].

1.2. Brief study methods

1.2.1. Who did we aim to include in the research?

In Wave 4, we contacted the 489 adults with learning disabilities in the UK in Cohort 1 who took part in Wave 3 and gave their consent to be approached about a future wave. For the booster sample of people from ethnic minority communities in England, we aimed to recruit an additional 100 people for Cohort 1 from England, to add to the Wave 4 sample living in England.

In Wave 4, in the UK we contacted the 280 family carers or support workers of people with learning disabilities who could not take part in an interview themselves (Cohort 2) who took part in Wave 3 and gave their consent to be approached about a future wave. For the booster sample of people from ethnic minority communities in England, we aimed to recruit an additional 50 family carers/support workers of people from ethnic minority communities for Cohort 2 to add to the Wave 4 sample living in England.

1.2.2. How did we develop the interview schedule and survey?

As with Waves 1-3, changes to the interview schedule and survey for Wave 4 were designed in consultation with groups of people with learning disabilities, family carers of people with profound and multiple learning disabilities (PMLD), and a range of policymaker stakeholders. We undertook this consultation following a number of steps:

1. We consulted with people with learning disabilities, partner groups and policy stakeholders from across the UK about current urgent and important issues for inclusion in the interview and survey at Wave 4, and which issues in the Wave 3 interview and surveys were less relevant for Wave 4;
2. We developed candidate sets of questions to retain and drop from the Wave 3 interview and survey and potential sets of new questions for Wave 4, and asked people with learning disabilities, partner groups and policy stakeholders to provide their feedback on the potential new sets of questions.

For Wave 4, after consultation, information sheets and consent forms were translated and made available in Urdu (India and Pakistan) and Punjabi (India and Pakistan) – surveys for family carers were also translated into these languages. Sessional interviewers with a range of spoken languages were trained and were available to conduct interviews.

1.2.3. How did we find people?

For Waves 1 and 2, recruitment of people into the study was facilitated through multiple methods, including through collaborating organisations, social media, and wider networks of learning disability and family organisations across England, Northern Ireland, Scotland, and Wales. Potential participants could express interest in the study via telephone, email, social media, or clicking a link to the survey (for family carers and support workers only) on the project website.

Wave 3 of data collection for this study followed up on participants who were recruited at Waves 1 and 2. No new participants were recruited into Wave 3.

For the main Wave 4 data collection, participants who took part in Wave 3 and had indicated their willingness to be approached about a future study Wave were contacted in August-November 2023.

We took the following steps to attempt to recruit a booster sample of people with learning disabilities and family carers from ethnic minorities at Wave 4.

- For Wave 4, after consultation, information sheets and consent forms were translated and made available in Urdu (India and Pakistan) and Punjabi (India and Pakistan) – surveys for family carers were also translated into these languages. Sessional interviewers with a range of spoken languages were trained and were available to conduct interviews.
- After consultation, we offered £30 vouchers for people with learning disabilities and family carers from ethnic minority communities to participate in the study.
- Learning Disability England commissioned a recruitment video specifically for this part of the study (see https://www.youtube.com/watch?v=RTw5nwT3dXM)
- Our main collaborating organisation in England, Learning Disability England, contacted and discussed the project with multiple self-advocacy groups and service provider organisations known to include people with learning disabilities from ethnic minority communities.
- Learning Disability England and the project team repeatedly shared information about this aspect of the study through social media and the Learning Disability England newsletter.
- We worked through learning disability social work and integrated health and social care teams in two local authority areas supporting substantial numbers of people with learning disabilities from ethnic minority communities. In each area we had workshops with relevant stakeholders, trained local sessional interviewers, and supported the local areas to share information about this aspect of the study.

1.2.4. How did we collect the data?

Data were collected between 1st September and 2nd December 2022 for Cohort 1, and between 29th September and 7th December 2022 for Cohort 2, with the bulk of data collected in September and October. The data collection window for people from ethnic minority communities (both interviews with people with learning disabilities and surveys with family carers) was extended until the end of January 2023.

1.2.4.1. Cohort 1: Adults with learning disabilities

For the data from Wave 4 of the study that is the subject of this report, we directly interviewed 101 adults with mild/moderate learning disabilities in England (Cohort 1), with an additional participant preferring to complete the schedule themselves using a paper copy of the schedule. Of the 102 people in Cohort 1 in England, 92 were part of the original cohort and a further 10 people from minority ethnic communities were recruited for the first time in Wave 4. Data were entered directly into Qualtrics™ during the interviews. Interviews were undertaken using the preferred digital platform or on the telephone for each participant: Zoom (57 people; 55.9%), telephone (17 people; 16.7%), Microsoft Teams (22 people; 21.6%), and WhatsApp (6 people; 5.9%).

Participants were also able to have a supporter of their choice (e.g., family member, support workers) present at the interview. In all cases, flexibility was paramount to ensure that people with learning disabilities were able to participate in their preferred way.

Interviews were usually completed in one sitting. Short breaks were offered during interviews when needed.

1.2.4.2. Cohort 2: Family carers and support workers of adults with severe/profound learning disabilities

We also collected information about a cohort of adults with learning disabilities who were not able to take part in an interview with a researcher. In most instances, these individuals were likely to have severe/profound learning disabilities. To gather data on this group, we surveyed their family carers or support workers using an online self-completion Qualtrics™ survey (Cohort 2), including versions of the survey in Urdu and Punjabi.

For this analysis, in Cohort 2 at Wave 4, participants were the family carers and support workers of 83 adults with learning disabilities in England. Three of these were recruited for the first time at Wave 4.

1.2.5. How did we analyse the data?

The analysis for Wave 4 reported here is descriptive, with percentage estimates relating to the responses for individual survey items. All analyses were conducted using SPSS v.27. Data from Cohort 1 and Cohort 2 were analysed separately. Descriptive comparisons concerning demographic data were conducted between the two cohorts and are presented in Section 2.

For both Cohort 1 and Cohort 2 there were too few people to allow for the analysis of the circumstances and experiences of people according to specific or even broadly defined ethnic groups. This means that this element of the Coronavirus and People with Learning Disabilities Study could not fulfil its stated aim.

Section 3 presents major differences between people from White British ethnic groups and people from a combined sample of any other ethnic group. We are acutely aware this is far from ideal – it ignores the high degree of diversity in circumstances and experiences of people across particular ethnic groups, and can serve to mask inequalities being experienced by specific ethnic groups. A lack of difference, for example, cannot be interpreted as similarity. Differences that we did find (pragmatically determined as a difference of at least 20 percentage points) are presented merely to point to issues that may be priorities for further, more focused attention.

2: Demographic information

2.1. Who took part?

At Wave 4, in Cohort 1 data were available for this report for 102 people with learning disabilities in England and, in Cohort 2 for 83 family carers or support workers of people with learning disabilities.

In this section of the report, we present information concerning the demographic characteristics of people with learning disabilities in Cohort 1 and Cohort 2.

2.1.1 Ethnicity

Table 2.1 presents the data concerning the ethnicity of people with learning disabilities in England at Wave 4 (separated by cohort), using the ethnic groups employed in the 2021 Census. For comparison, percentages for the general population of England aged 16 or over, calculated from ONS 2021 data[3], are also provided in the table. There is, however, no public information available on the number of adults with learning disabilities across different ethnic groups in England.

With the 10 people added to the Wave 4 Cohort 1 group, people with an ethnic identity other than White English, Welsh, Scottish, Northern Irish or British constituted 22.5% of the Cohort 1 sample. These 23 people reported themselves to be in one of nine ethnic groups, with no more than four people in any one ethnic group.

For Cohort 2, at Wave 4 people with an ethnic identity other than White English, Welsh, Scottish, Northern Irish or British constituted 13.4% of the Cohort 2 sample. These 11 people were reported to be in one of seven ethnic groups, with no more than three people in any one ethnic group.

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[3] Office for National Statistics. Dataset: Ethnic group by age and sex in England and Wales. Release date 23 January 2023. https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/ethnicity/datasets/ethnicgroupbyageandsexinenglandandwales

Table 2.1. Ethnicity data for the people with learning disabilities at Wave 4, separated by study cohort

	Cohort 1 (N = 102)	**Cohort 2 (N = 83)**	**England Age 16+ (2021 Census)**
Ethnicity			
Asian			
Indian	2 (2.0%)	1 (1.2%)	3.2%
Pakistani	2 (2.0%)	0 (0.0%)	2.4%
Bangladeshi	0 (0.0%)	0 (0.0%)	1.0%
Chinese	0 (0.0%)	0 (0.0%)	0.8%
Any other Asian background	0 (0.0%)	3 (3.6%)	1.6%
Black			
Caribbean	4 (3.9%)	0 (0.0%)	1.2%
African	1 (1.0%)	0 (0.0%)	2.4%
Any other Black, Black British, or Caribbean background	4 (3.9%)	0 (0.0%)	0.4%
Mixed/multiple			
White and Black Caribbean	4 (3.9%)	1 (1.2%)	0.6%
White and Black African	0 (0.0%)	0 (0.0%)	0.3%
White and Asian	1 (1.0%)	2 (2.4%)	0.5%
Any other Mixed or multiple ethnic background	3 (2.9%)	2 (2.4%)	0.6%
White			
English, Welsh, Scottish, Northern Irish or British	79 (77.5%)	71 (85.5%)	75.1%
Irish	0 (0.0%)	1 (1.2%)	1.0%
Gypsy or Irish Traveller	0 (0.0%)	1 (1.2%)	0.1%
Roma	0 (0.0%)	0 (0.0%)	0.2%
Any other White background	2 (2.0%)	0 (0.0%)	6.6%
Other			
Arab	0 (0.0%)	0 (0.0%)	0.5%
Any other ethnic group	0 (0.0%)	0 (0.0%)	1.6%
I do not want to answer this question	0 (0.0%)	1 (1.2%)	

2.1.2 Other demographic data

Table 2.2 below shows data on gender, age band, whether the person is identified as a person with Down syndrome or is identified as an autistic person, and for Cohort 2 whether the person is identified as a person with profound and multiple learning disabilities (PMLD) and what the relationship of the person completing the survey is to the person with learning disabilities. All of these data are broken down by two very broad composite ethnicity groups (White English, Scottish, Welsh, Northern Irish or British; compared to any other ethnic group).

In Cohort 1, both groups were broadly similar: a majority of men and the majority of people being under 45 years old, with less than 10% of people with Down syndrome and a substantial minority of people identified as autistic.

In Cohort 2 both groups were also broadly similar: a majority of men and the majority of people being under 45 years old, a majority of people diagnosed by a professional as autistic, and substantial minorities of people with Down syndrome and/or profound and multiple learning disabilities (PMLD). In Cohort 2, over 80% of people completing the survey were family carers.

Table 2.2. Demographic data for the people with learning disabilities at Wave 4, separated by study cohort and ethnicity

	Cohort 1 (N = 102)		**Cohort 2 (N = 82)**	
	White English, Scottish, Welsh, Northern Irish, British (n=79)	**Any other ethnic group (n=23)**	**White English, Scottish, Welsh, Northern Irish, British (n=71)**	**Any other ethnic group (n=11)**
Gender				
Male	58%	65%	61%	55%
Female	42%	31%	36%	45%
Other	0%	4%	3%	0%
Age				
16-24	5%	17%	19%	27%
25-34	24%	26%	39%	18%
35-44	29%	30%	20%	27%
45-54	25%	9%	9%	27%
55-64	13%	13%	10%	0%
65+	3%	4%	4%	0%
Relationship to person cared for				
Family Carer	n/a	n/a	89%	82%
Paid Support Worker	n/a	n/a	3%	9%
Other e.g. friend	n/a	n/a	9%	9%
Does “PMLD” apply to the person with learning disabilities				
Yes	n/a	n/a	27%	36%
No	n/a	n/a	62%	55%
Don’t know	n/a	n/a	11%	9%
Down syndrome	9%	4%	20%	27%
Professional label of autism or Asperger’s syndrome				
Yes	29%	35%	61%	55%
No, but self-identifies or carer/supporter identifies person as autistic	1%	0%	11%	9%

NB. Where a table cell states n/a, this indicates that the option was not available in that survey. This applies throughout this report.

Table 2.3 below shows data on where people were living and, for Cohort 1, whether the person with learning disabilities looked after someone they lived with. All of these data are broken down by very broad composite ethnicity groups (White English, Scottish, Welsh, Northern Irish or British compared to any other ethnic group).

In Cohort 1, people from White English/Scottish/Welsh/Northern Irish/British ethnic groups and people from any other ethnic group most commonly lived with their family with no support (19% vs 30%), or with other people with learning disabilities with support workers coming into their home during the day and night (22% vs 22%). People from White English/Scottish/Welsh/Northern Irish/British people ethnic groups were also commonly living alone with support in supported living, privately rented, or privately owned accommodation (24% vs 9%), whereas people from any other ethnic group were also commonly living with other people with learning disabilities with support workers coming into their home during the day (3% vs 17%).

In Cohort 2, across both broad collections of ethnic groups people’s living situations were similar, most commonly living with family with no support staff, living with family with support staff coming into the family home, living with other people with learning disabilities with support (either in supported living or residential care), or living alone in supported living with support from staff.

Table 2.3. Who people with learning disabilities live with (Wave 4 participants)

	Cohort 1 (N = 102)		**Cohort 2 (N = 82)**	
	White English, Scottish, Welsh, Northern Irish, British (n=79)	**Any other ethnic group (n=23)**	**White English, Scottish, Welsh, Northern Irish, British (n=71)**	**Any other ethnic group (n=11)**
Who does the person with learning disabilities live with?				
Live alone with no support from staff	6%	9%	1%	0%
Live alone with support in supported living, privately rented, or privately owned accommodation	24%	9%	13%	18%
Live with their partner with no support from staff	6%	0%	0%	0%
Live with their partner with support workers coming into their home	4%	4%	0%	0%
Live with family with no support from staff	29%	30%	30%	36%
Live with family with support workers coming into their home	4%	9%	16%	18%
Live in supported/independent	1%	0%	0%	0%

living, but have moved back to family home because of COVID-19				
Live in a Shared Lives arrangement	1%	0%	3%	9%
Live with other people with learning disabilities with no support from staff	0%	0%	0%	0%
Live with other people with learning disabilities with support workers coming into their home during the day	3%	17%	n/a	n/a
Live with other people with learning disabilities with support workers coming into their home during the day and night	22%	22%	n/a	n/a
Live with other people with support in supported living accommodation	n/a	n/a	14%	9%
Live with other people with support in residential care	n/a	n/a	17%	9%
Live with other people with learning disabilities with support, with home ownership	0%	0%	0%	0%
Live in a secure placement	0%	0%	0%	0%
Live in a different type of home	0%	0%	7%	0%
The person with learning disabilities looks after someone they live with (N = 74)	18%	21%	n/a	n/a

3: Differences between people from White British ethnic groups vs. any other ethnic group

For Cohort 1 there were 79 people from White English/Scottish/Welsh/Northern Irish/British ethnic groups (called throughout this section White British ethnic groups) and 23 people from any other ethnic group, and for Cohort 2 there was survey information about 71 people from White British ethnic groups and 11 people from any other ethnic group. This was too few people to allow for the analysis of the circumstances and experiences of people according to specific or even broadly defined ethnic groups.

This section presents major differences between people from White British ethnic groups and people from any other ethnic group, pragmatically determined as a difference of at least 20 percentage points, that are presented to point to issues that may be priorities for more focused attention.

3.1. COVID-19

In Cohort 1 at Wave 4, everyone (100%) in the White British ethnic groups had received at least one dose of a COVID-19 vaccine, with the vast majority of people (85%) having received three or four doses. For people from any other ethnic group in Cohort 1, the vast majority of people (83%) had received at least one dose of a COVID-19 vaccine, with 65% of people having had three or four doses.

At Wave 4, people in Cohort 1 in White British ethnic groups compared to any other ethnic group were less likely (33% vs 61%) and in Cohort 2 more likely (42% vs 18%) to be washing their hands more than before the COVID-19 pandemic.

3.2. Health and access to health services

In Cohort 2, at Wave 4 the family carer/support worker rated health of people from White British ethnic groups was more likely to be rated as good (51% vs 27%), and less likely to be rated as OK (32% vs 64%) compared to people from any other ethnic group.

In Cohort 1 at Wave 4, people from White British ethnic groups were more likely than people from any other ethnic group to say that it was not easy to contact their GP (35% vs 9%) and less likely to say that someone else contacted the GP for them (22% vs 48%). Family carers/support workers of people in Cohort 2 from any other ethnic group were more likely than people from White British ethnic groups to always see the same GP (46% vs 24%).

In Cohort 2, 24% of people from the White British ethnic groups and 55% of people from any other ethnic group had been in contact with another type of health service therapist (e.g. a physiotherapist, occupational therapist or speech and language therapist) in the last four weeks, with the most common contact being in person (16% vs 45%).

At Wave 4, over a quarter of people in Cohort 2 from White British ethnic groups but no-one from any other ethnic group was reported to be waiting for a planned medical test (27% vs 0%), with higher proportions also reporting waiting for a planned hospital appointment (38% vs 18%).

3.3. Wellbeing and mental health

People in Cohort 1 were asked about worries relating to the COVID-19 pandemic. At Wave 4, people from any other ethnic group were more likely than people from White British ethnic groups to be worried a lot about giving COVID-19 to someone else (44% vs 23%), and the amount of money coming in (26% vs 6%).

When people in Cohort 1 were asked about their wellbeing in the last four weeks, at Wave 4 people from any other ethnic group were more likely than people from White British ethnic groups to report feeling lonely at least some of the time (57% vs 33%), and worried at least some of the time (83% vs 63%).

People in Cohort 2 from any other ethnic group were less likely than people from White British groups to have got help if they were feeling sad/down, worried/anxious, or angry/frustrated, from family (36% vs 64%) or paid support workers (18% vs 49%).

3.4. Relationships, social lives, and digital inclusion

In Cohort 1, people from White British ethnic groups were more likely than people from any other ethnic group to see family at least once a week (70% vs 38%), and more likely to see friends at least once a week (92% vs 63%).

In Cohort 2, more people from the White British ethnic groups (66%) than people from any other ethnic group (27%) were using the internet at home.

3.5. Access to service support

Family carers/support workers of people in Cohort 2 from White British ethnic groups were more likely than family carers/support workers of people from any other ethnic group to prefer to talk to their social worker face to face (53% vs 29%).

In Cohort 2, 39% of people from White British ethnic groups and 18% of people from any other ethnic group had gone to a day service outside their home in the last four weeks.

In Cohort 2, 64% of people from White British ethnic groups and 36% of people from any other ethnic group had gone to community activities outside their home in the last four weeks.

According to family carers/support workers of people in Cohort 2 who were supported by PAs/support workers at home, more people in Cohort 2 from White British ethnic groups (90%) than people from any other ethnic group (50%) liked most or all of the PAs/support workers who supported them at home.

At Wave 4 over half of family carers of people in Cohort 2 from White British ethnic groups (53%) and a third of family carers of people from any other ethnic group (33%) said that in the last four weeks they had had to step in and carry out work previously done by a paid support worker.

3.6. Leaving the house and getting around

At Wave 4, people in Cohort 1 from White British ethnic groups were less likely than people from any other ethnic group to go out of the house in the last week to use public transport (61% vs 82%) or to do exercise/sport in a gym/sports hall (18% vs 48%), but were more likely to go to a café, bar or restaurant (67% vs 44%).

At Wave 4, people in Cohort 2 from White British groups were less likely than people from any other ethnic group to have left the house in the last week to go out in a private car (65% vs 91%).

For people in Cohort 1 at Wave 4, people from White British ethnic groups were less likely than people from any other ethnic group to get to places by: using the bus or tram (71% vs 91%), using taxis (22% vs 44%) or using the train/metro/tube (19% vs 44%).

For people in Cohort 2 at Wave 4, people from White British groups were more likely than people from any other ethnic group to get to places by using taxis (25% vs 0%).

More people in Cohort 2 from White British ethnic groups (86%) compared to any other ethnic group (64%) were reported by family carers/support workers to like living in their neighbourhood.

3.7. Health and wellbeing of family carers

At Wave 4, 20% of family carers of people in Cohort 2 from White British ethnic groups compared to no family carers of people from any other ethnic group reported their own health as family carers to be very good or excellent.

4: Conclusions and recommendations

4.1. Conclusions

This part of the Coronavirus and people with learning disabilities study did not achieve its aims of recruiting sufficient additional numbers of people with learning disabilities and family carers/support workers of people with learning disabilities from ethnic minorities to allow for meaningfully detailed comparisons of people's circumstances, experiences, health and wellbeing across ethnic groups. We are acutely aware this is far from ideal – it ignores the high degree of diversity in circumstances and experiences of people across particular ethnic groups, and can serve to mask inequalities being experienced by specific ethnic groups. A lack of difference, for example, cannot be interpreted as similarity.

Broad brush comparisons between people with learning disabilities from White British ethnic groups and people from any other ethnic group, in both cohorts, did not show a consistent pattern of differences in terms of access to health care, although a greater proportion of people in White British ethnic groups with greater support needs (Cohort 2) were accessing a range of social care services compared to people from any other ethnic group. Health, wellbeing and social connectedness were consistently poorer for people from any other ethnic group compared to people from White British ethnic groups across a range of indicators, and an indicator of the health of family carers was also poorer for those supporting a person from any other ethnic group. This wide range of continuing inequalities is consistent with general population data for England showing similarly pervasive inequalities amongst people from ethnic minority communities[4], and strongly suggests that policy attention and initiatives directed towards tackling these inequalities should ensure they include people with learning disabilities.

4.2. Recruiting people with learning disabilities and families

We clearly fell far short of our aims in terms of recruiting people with learning disabilities and family members from ethnic minority communities. While the study team worked with and through multiple organisations with much closer connections to diverse areas, services and supports, this was not sufficient to recruit substantial additional numbers of participants. Vouchers for participation, recommended by a number of organisations working with people from ethnic minority communities, had no impact on recruitment. For Wave 4, we also continued conducting interviews online and it was suggested by at least one organisation (at the end of the data collection period) that offering an option to conduct interviews face-to-face may have increased the number of people willing to take part. Overall, the study was being conducted by a largely White British research team on a relatively short timescale,

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[4] Ethnicity and COVID-19 (undated). UK Government Race Disparity Unit. https://www.ethnicity-facts-figures.service.gov.uk/covid-19

and translated versions of materials were available later than English language versions.

We also had no population information to guide us when considering the numbers of people with learning disabilities from particular ethnic groups. There are no public statistics on the number of adults with learning disabilities from minority ethnic communities using social care in England and the ethnicity of people with learning disabilities is poorly and inconsistently recorded in healthcare systems[5]; although the number of adults with learning disabilities from these communities needing social care support is projected to rise substantially[6].

4.3. Diversity and intersectionality

Although the numbers of people with learning disabilities in the study from ethnic groups other than White British ethnic groups were relatively small, there was a high degree of ethnic diversity within both the Cohort 1 and Cohort 2 samples. This included people of dual heritage and people from White ethnic groups that were not British. Given such ethnic diversity, recruiting sufficient people to enable meaningfully specific comparisons across ethnic groups would have required more than the planned 100 people with learning disabilities and 50 family carers/support workers aimed it in this part of the study.

A recent NIHR add-on project[7] run by a community organisation with longstanding roots in ethnically diverse communities focused on the experiences of adults with learning disabilities and autistic people from South Asian, Black African and African Caribbean communities, as well as individuals with dual heritage. This project highlighted the importance of intersectionality in the lives of the people with learning disabilities they worked with, identifying a failure of services to recognise the whole person; an individual is not just disabled, they also have an ethnicity and these two aspects of their lives (with others such as gender) intersect and form their experiences. It might be argued that larger-scale quantitative study designs such as that underpinning the Coronavirus and people with learning disabilities study, in isolation, are not well placed to explore the complexities of intersectionality and certainly without clear sampling strategies focused on key ethnicity groups.

4.4. Recommendations

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[5] Chauhan U, Umpleby K, Roberts C, Hatton C, Chesterton L, Cooper-Moss N, Butt J, Clark S, Garner C & Ditzel N (forthcoming a). *We deserve better: Ethnic minorities with a learning disability and access to healthcare Part A – a review of policy and data*. Leeds: NHS Race & Health Observatory.

[6] Emerson E, Robertson J, Coles B & Hatton C (2012). *The future need for social care services for adults with disabilities in England 2012-2030*. London: SSCR. https://www.sscr.nihr.ac.uk/wp-content/uploads/SSCR-research-findings_RF005.pdf

[7] Leeson J & Dunstan L (2022). *Small Margins: Working with people with a learning disability and autistic people from minority ethnic communities*. Changing Our Lives online. (https://changingourlives.org/wp-content/uploads/2023/03/Small-Margins.pdf).

Because the conclusions to be drawn from this part of the Coronavirus and People with Learning Disabilities Study are so limited, there are few policy recommendations to be made.

The major recommendation here is for policymakers, commissioners and professionals to pay more attention to understanding the health and wellbeing of people with learning disabilities from specific ethnic minority communities, and to draw up responses to health and wellbeing needs. Poorer health and wellbeing, along with a lack of social connection and for people with greater support needs poorer access to social care services, requires responses that respect the intersectionality of people with learning disabilities with particular ethnic identities (including dual heritage identities).

In terms of future research concerning people with learning disabilities from ethnic minority communities, there are a number of implications emerging from this study.

First, although detailed ethnic comparisons may not be possible, it is crucial that large-scale studies of people with learning disabilities utilise methods that include people from ethnicity minority communities, if any claims to representativeness are to be made. It is worth noting that there is currently no public data on the ethnic composition of the population of adults with learning disabilities in England[8], and robust data are needed for researchers to be able to determine the extent to which the people included in research projects are representative of the population of people with learning disabilities. However, given the ethnic diversity of the population of people with learning disabilities, it is unlikely that such approaches alone will include sufficient numbers of people with learning disabilities in particular ethnic groups to allow for in-depth analysis related to people's ethnicity.

Second, it follows from the above and from other recent research[9] that in-depth work with people with learning disabilities from particular ethnic minority communities is required to understand and develop policy and practice solutions to tackle the inequities and discrimination that people from these communities undoubtedly experience[10]. Such research is also well-placed to explore the complexities of

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[8] Chauhan U, Umpleby K, Roberts C, Hatton C, Chesterton L, Cooper-Moss N, Butt J, Clark S, Garner C & Ditzel N (forthcoming a). *We deserve better: Ethnic minorities with a learning disability and access to healthcare Part A – a review of policy and data*. Leeds: NHS Race & Health Observatory.

[9] Leeson J & Dunstan L (2022). *Small Margins: Working with people with a learning disability and autistic people from minority ethnic communities*. Changing Our Lives online. (https://changingourlives.org/wp-content/uploads/2023/03/Small-Margins.pdf).
Chauhan U, Umpleby K, Roberts C, Hatton C, Chesterton L, Cooper-Moss N, Butt J, Clark S, Garner C & Ditzel N (forthcoming b). *We deserve better: Ethnic minorities with a learning disability and access to healthcare Part B – an exploration of lived experiences*. Leeds: NHS Race & Health Observatory.

[10] Leeson J & Dunstan L (2022). *Small Margins: Working with people with a learning disability and autistic people from minority ethnic communities*. Changing Our Lives online. (https://changingourlives.org/wp-content/uploads/2023/03/Small-Margins.pdf).

intersectionality. Research can often mirror health and social care services in only attending to one aspect of identity at a time, which can be overly reductive when considering how people want to live their lives and how people can be supported in ways that ensure people's complete identities are respected and embraced.

Third, our experience in this project is that, despite extensive efforts and working with well-connected collaborating organisations, largely white academic research groups have not been very successful in connecting with substantial communities of people with learning disabilities (and their families) from ethnic minority communities. Smaller projects led by well-established organisations with strong community connections have been much more successful in this respect[11]. This suggests developing and supporting different kinds of working relationships between communities, community organisations and academic research groups, which would take time to establish and which would generate research/knowledge generation activities more rooted in the interests of communities. It is also crucial that academic research groups become both more diverse, and more open in terms of the range of skills, interests and activities that count as 'academic'.

Chauhan U, Umpleby K, Roberts C, Hatton C, Chesterton L, Cooper-Moss N, Butt J, Clark S, Garner C & Ditzel N (forthcoming a). *We deserve better: Ethnic minorities with a learning disability and access to healthcare Part A – a review of policy and data*. Leeds: NHS Race & Health Observatory.
Chauhan U, Umpleby K, Roberts C, Hatton C, Chesterton L, Cooper-Moss N, Butt J, Clark S, Garner C & Ditzel N (forthcoming b). *We deserve better: Ethnic minorities with a learning disability and access to healthcare Part B – an exploration of lived experiences*. Leeds: NHS Race & Health Observatory.
Robertson J, Raghavan R, Emerson E, Baines S & Hatton C (2019). What do we know about the health and healthcare of people with intellectual disabilities from minority ethnic groups in the United Kingdom? A systematic review. *Journal of Applied Research in Intellectual Disabilities*, 32, 1310-1334. DOI: 10.1111/jar.12630.

[11] Leeson J & Dunstan L (2022). *Small Margins: Working with people with a learning disability and autistic people from minority ethnic communities*. Changing Our Lives online. (https://changingourlives.org/wp-content/uploads/2023/03/Small-Margins.pdf).