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# Health and healthcare of people with learning disabilities in the United Kingdom through the COVID-19 pandemic

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## Abstract

**Background:** During the COVID-19 pandemic in the United Kingdom, many health services were withdrawn from people with learning disabilities, with negative impacts on people's health. What has happened to people's health and healthcare as we move beyond the pandemic?

**Methods:** Access to health services and health status were tracked for 550 UK adults with learning disabilities, using structured online interviews with people with learning disabilities and online surveys with family members or paid carers. Information was provided four times, from Wave 1 (in the winter 2020/2021 'lockdown') to Wave 4 (autumn 2022, over a year after public health protections stopped).

**Findings:** By Wave 4, most people with learning disabilities had had COVID-19, although high vaccination rates limited the number of people hospitalised. There was little evidence that use of GP services, community nurses, other therapists or annual health checks had increased over time, and at Wave 4 more people were having difficulty getting their medicines. People's health did not substantially improve over time. People with profound and multiple learning disabilities had poorer health and were less likely to be accessing health services.

**Conclusions:** Improvements in access to health services for people with learning disabilities after the pandemic have not yet happened.

## KEYWORDS

health, health and social care policy and practice, learning (intellectual) disabilities

## Accessible Summaries

- Many health services stopped for people with learning disabilities in the COVID-19 pandemic, with a bad impact on people's health. What has happened

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to people's health and how they use health services through the COVID-19 pandemic and beyond?

- People and families told us about the health of over 500 people with learning disabilities living in the United Kingdom four times, from the national lockdown in winter 2020/2021 through to autumn 2022.
- A lot of people were still not getting the health services they needed after the end of the pandemic, and people's health was not getting better.
- People with profound and multiple learning disabilities had worse health but were not in contact with health services as much as other people with learning disabilities.

## 1 | INTRODUCTION

There is ample evidence that the health inequalities experienced by people with learning disabilities in the United Kingdom before the COVID-19 pandemic (Heslop et al., 2021) have worsened as a result of the COVID-19 pandemic. People with learning disabilities in the United Kingdom were much more likely to be hospitalised and to die of COVID-19 than other people, with standard mortality rates 3–6 times higher for people with learning disabilities compared to people without learning disabilities (Henderson et al., 2022; Office for National Statistics, 2021; Sosenko et al., 2023). People with learning disabilities were also less likely to receive intensive treatment if hospitalised for COVID-19 (Baksh et al., 2021). While COVID-19 vaccination rates for people with learning disabilities as a whole in the United Kingdom have been broadly comparable to the rest of the population (OpenSAFELY, 2022), there have been many reports both in the United Kingdom and internationally (Flynn, Bailey, et al., 2021; Flynn, Hatton, et al., 2021; Keenan & Doody, 2023; Scherer et al., 2023; Taggart et al., 2022) of pervasive disruptions to and withdrawal of a range of health services during the COVID-19 pandemic, which appears to have been a common experience across many countries. A recently updated scoping review (Keenan & Doody, 2023) on the reported effects of the COVID-19 pandemic on people with learning disabilities and their carers has noted a continuing trend towards the publication of commentaries and opinion pieces rather than primary research: 'Redirecting greater energies to research and less to professional debates and polemic activities may better serve people with intellectual disability and their carers' (p. 34). They also note that almost all the published research relates to research undertaken early in the pandemic, 'therefore the medium-long term effects of COVID-19 are still poorly understood' (p. 34).

This paper presents information on health status and health service access for over 500 adults with learning disabilities across the United Kingdom into the 'postpandemic' period, tracking people's experiences at three time points during the pandemic into a fourth time point in the autumn of 2022, over a year after public health

protections were generally lifted. The aims of this paper are to investigate issues relating to COVID-19, physical health and access to health services over time for adults with learning disabilities in the United Kingdom and to investigate potential associations with demographic factors and living circumstances.

## 2 | METHODS

### 2.1 | Design

The design of the research project from which data has been drawn for this paper was a longitudinal cohort study of adults with learning disabilities across the United Kingdom at four time points throughout and beyond the COVID-19 pandemic. Two groups of participants were: adults with learning disabilities who were interviewed by a researcher online using a structured interview schedule (Cohort 1) and adults with learning disabilities who would not be able to take part in an interview, where family carers and support workers acted as proxy informants via an online survey (Cohort 2).

### 2.2 | Participants

Selected demographic information is presented in Table 1 for both cohorts at Wave 4 of the study. People from all four countries in the United Kingdom were well represented (see Table 1), although the unavailability of reliable demographic information about the population of adults with learning disabilities in the United Kingdom makes comparisons impossible.

For Cohort 1, most of the participants were aged 16–44 years (69.4%), just over half were men (51.4%), the vast majority were White British (89.6%), 23.3% were also autistic and 11.5% were people with Down syndrome. Substantial proportions of people in Cohort 1 were living with their family (41.0%), living alone or with a partner (36.5%) or living with other people with learning disabilities in some form of supported housing or residential accommodation

**TABLE 1** Demographic and living circumstances of participants at Wave 4.

	Cohort 1 (Wave 4 n = 358)	Cohort 2 (Wave 4 n = 192)
<b>Gender (Wave 4)</b>		
Man	182 (51.4%)	106 (55.2%)
Woman	168 (47.5%)	84 (43.8%)
Other	3 (0.9%)	0 (0.0%)
Do not want to answer	1 (0.3%)	2 (1.0%)
<b>Age (Wave 4)</b>		
16–24	31 (8.9%)	50 (26.3%)
25–34	112 (32.1%)	72 (37.9%)
35–44	99 (28.4%)	39 (20.5%)
45–54	56 (16.0%)	15 (7.9%)
55–64	37 (10.6%)	9 (4.7%)
65+	14 (4.0%)	5 (2.6%)
<b>Ethnicity (Wave 4)</b>		
White British	318 (89.6%)	172 (89.6%)
White–Irish, Roma, Gypsy or Irish Traveller, Other	14 (4.0%)	10 (5.2%)
Asian	4 (1.2%)	4 (2.1%)
Black	11 (3.1%)	0 (0.0%)
Mixed/multiple ethnicities	6 (1.7%)	5 (2.6%)
Do not want to answer	2 (0.6%)	1 (0.5%)
<b>Down syndrome (Wave 4)</b>		
Yes	41 (11.5%)	42 (21.9%)
<b>Professional label of autism or Asperger's syndrome (Wave 4)</b>		
Yes	78 (21.9%)	91 (47.9%)
No, but waiting for an assessment or self-identifies (Cohort 1) or carer/supporter identifies person (Cohort 2) as autistic	5 (1.4%)	22 (11.6%)
<b>Term 'Profound and multiple learning disabilities' (PMLD) applies to person</b>		
Yes		86 (44.8%)
<b>Country the participant lives in (Wave 4)</b>		
England	93 (26.0%)	80 (41.7%)
Northern Ireland	63 (17.6%)	20 (10.4%)
Scotland	89 (24.9%)	56 (29.2%)
Wales	113 (31.6%)	36 (18.8%)
<b>Living situation (Wave 4)</b>		
Lives alone with no support from staff	28 (7.9%)	1 (0.5%)
Lives alone with support staff coming into home	82 (23.0%)	18 (9.4%)

**TABLE 1** (Continued)

	Cohort 1 (Wave 4 n = 358)	Cohort 2 (Wave 4 n = 192)
Lives with partner with no support from staff	11 (3.1%)	0 (0.0%)
Lives with partner with support staff coming into home	9 (2.5%)	0 (0.0%)
Lives with family with no support from staff	132 (37.1%)	76 (39.8%)
Lives with family with support staff coming into home	14 (3.9%)	38 (19.9%)
Lives in a Shared Lives arrangement	4 (1.1%)	6 (3.1%)
Lives with other people with learning disabilities, with support staff coming into home	74 (20.8%)	47 (24.6%)
Lives in other living situations	2 (0.6%)	5 (2.6%)
<b>Person looks after someone they live with (Wave 4, n = 248)</b>		
Yes	30 (12.1%)	
<b>Cohort 2 only—relationship of the respondent to the person with intellectual disabilities</b>		
Family carer		179 (93.2%)
Support worker or paid carer		11 (5.7%)
Shared lives carer		2 (1.0%)

(20.8%). Amongst those people not living alone, 12.1% reported looking after someone they lived with.

For Cohort 2 most people with learning disabilities were aged 16–44 (84.7%), a majority were men (55.2%), and the vast majority were White British (89.6%). Respondents reported that the term 'profound and multiple learning disabilities' (PMLD) applied to almost half of people in Cohort 2 (44.8%) and 21.9% were people with Down syndrome. Most adults with learning disabilities in Cohort 2 were living with their family (63.3%), relatively few people were living alone (10.6%), and a quarter of people were living with other people with learning disabilities, usually in some form of supported housing or residential accommodation (26.1%). Further information about participants can be found in Flynn, Bailey, et al. (2021) and Hatton et al. (2023).

## 2.3 | Measures

The selection and wording of survey questions was finalised through extensive consultation with groups of people with learning disabilities (particularly for Cohort 1 interviews) and family organisations (particularly for Cohort 2 surveys) at each data collection wave, to

maximise relevance and accessibility. Due to changing circumstances throughout the project, the inclusion and wording of questions could vary from wave—the wording of questions is clearly indicated in each table.

The structured interview schedule and online survey covered a wide range of topics, including questions related to COVID-19, mental and physical health and wellbeing, access to health and social care services, social lives and social networks, activities within and outside the home, experiences of bereavement, digital inclusion and cost of living. For the analyses included in this paper, questions focused on demographic factors, physical health generally and COVID-19 specifically, and access to a range of health services. Responses reported by very small numbers of people (e.g. participants with a gender identity other than man or woman) were collapsed into broader categories or excluded from the specific analyses involving the relevant question, but these participants were included in all other analyses (e.g. people identifying as a gender other than male or female were excluded from analyses concerning gender differences, but were included in all other analyses).

## 2.4 | Procedure

The study took place in four waves: Wave 1 December 2020–February 2021 (during a national UK ‘lockdown’); Wave 2 April 2021–May 2021 (as public health protections were beginning to ease); Wave 3 July 2021–August 2021 (when, at least in England, almost all public health protections were removed); Wave 4 September 2022–December 2022 (largely in the months of October and November, when public health protections and free COVID testing had stopped).

New participants into the study were recruited at Waves 1 and 2, facilitated through multiple methods across the United Kingdom, including through collaborating organisations in each country, social media and wider networks of learning disability and family organisations across England, Northern Ireland, Scotland and Wales. At Wave 2, both Wave 1 participants and new participants were invited to take part. At Wave 3, participants who had taken part in Wave 1 or Wave 2 (or both) were invited to take part. At Wave 4, participants who had taken part in Wave 3 and indicated a willingness to be contacted about a future wave were invited to take part.

The imperative of the project to recruit and collect data for rapid feedback to policymakers, coupled with restrictions associated with the COVID-19 pandemic, meant that potential participants (and proxy informants) identified themselves or the person they were caring for/supporting as a person with learning disabilities. No information was asked about ‘level’ of learning disability, although it was assumed that people with profound and multiple learning disabilities would not be taking part directly in the Cohort 1 structured interviews. Recruitment was to a certain extent opportunistic, although attempts were made to ensure diversity in gender, age, ethnicity and living situation across the samples. Potential participants could express interest in the study via telephone, e-mail, social media or clicking a link to the survey (for family carers and support

staff only) on the research project website. Contact details of people who had indicated an interest in taking part in Cohort 1 were sent to research teams in the relevant country, who contacted each person to talk through the project and send them the easy read participant information sheet. If people were still interested in taking part, at least 24 h later, the interviewer arranged to go through the consent process and, if the person consented, conduct the interview. For Cohort 2, the survey was available online and included extensive participant information and consent questions before the survey started. No participants received an honorarium for participating.

For Waves 3 and 4, participants who had taken part in previous waves and indicated a willingness to be contacted again were invited to take part.

For Cohort 1, trained research interviewers directly interviewed adults with learning disabilities via Zoom™, telephone, Microsoft Teams™, WhatsApp™ video call, Messenger™ video call, or FaceTime™, depending on the interviewee's preference. All interviewees had the capacity to take part in the interviews and gave their consent to do so before the interview was conducted. Data were entered directly into Qualtrics™ during the interviews by the interviewers. Three people preferred to self-complete an online version of the survey, which was made available to them at their request. Participants could also have a supporter of their choice (e.g. family member, support staff) present at the interview. In all cases, flexibility was paramount to ensure that people with learning disabilities could participate in their preferred way. Interviews typically took 45 min and were usually completed in one sitting. Short breaks were offered during interviews when needed. All interviewers had experience of research interviewing and were trained via online training sessions within each country, with regular supervision for interviewers.

For Cohort 2, information was collected via an online Qualtrics™ survey about adults with learning disabilities who were not able to take part in an interview with a researcher. To gather data on this group, we surveyed their family carers or paid support staff. At Wave 4, 93.2% of respondents were family carers of an adult with learning disabilities and 5.7% of respondents were paid support staff of an adult with learning disabilities. The remaining 1.0% of respondents were other people who knew the adult with learning disabilities very well (e.g. a friend). Further information concerning the structured interview and survey methods can be found in Flynn, Bailey, et al. (2021) and Hatton et al. (2023).

## 2.5 | Data analysis

In Cohort 1, 358 people with learning disabilities were interviewed at Wave 4. Of these 358 people, linked participant information was available for 321 people at Wave 1, 331 people at Wave 2 and 341 people at Wave 3.

In Cohort 2, we received completed online surveys at Wave 4 concerning 192 people with learning disabilities. Of these 192, we had linked information for 176 people at Wave 1, 164 people at Wave 2 and 174 people at Wave 3.

**TABLE 2** Factors related to COVID-19.

	Cohort 1 (Wave 4 n = 358)	Cohort 2 (Wave 4 n = 192)
Do you think the person with learning disabilities has ever had coronavirus?		
Wave 1—Yes	22 (6.9%)	17 (9.7%)
Wave 2—Yes	29 (8.8%)	15 (9.1%)
Wave 3—Yes	30 (8.9%)	19 (10.9%)
Wave 4—Yes	218 (61.2%)	127 (66.1%)
Has the person been in hospital because of any coronavirus symptoms? (of those who have had coronavirus)		
Wave 1—Yes	5 (22.7%)	1 (5.9%)
Wave 2—Yes	4 (13.8%)	1 (6.7%)
Wave 3—Yes	5 (16.7%)	1 (5.3%)
Wave 4—Yes	9 (4.1%)	2 (1.6%)
Is the person shielding now?		
Wave 1—Yes	59 (18.4%)	87 (49.4%)
Wave 2—Yes	29 (8.7%)	64 (39.2%)
Wave 3—Yes	10 (3.0%)	40 (23.0%)
Wave 4—Yes	1 (0.3%)	4 (2.1%)
Has the person had at least one dose of the coronavirus vaccine?		
Wave 1—Yes	62 (19.3%)	12 (6.8%)
Wave 2—Yes	303 (91.8%)	148 (90.2%)
Wave 3—Yes	330 (97.3%)	165 (94.8%)
Wave 4—Yes	346 (97.2%)	183 (95.3%)

Cohort 1 and Cohort 2 datasets were analysed separately throughout, using SPSS 28™. Descriptive data are presented for all waves with relevant data in Tables 2–4.

For categorical variables at Wave 4, potential associations between demographic/living circumstances variables and factors relating to physical health/access to health services were analysed using Fisher's exact test (for 2 × 2 tables) or Chi-square (for larger tables). All tests were two-sided, using a significance level of  $p < 0.01$  to make an adjustment for multiple testing. The demographic and living circumstances variables used in these analyses were collapsed into categories to ensure sufficient numbers in each category: country (England, Northern Ireland, Scotland and Wales); gender (male and female); age band (16–44 years, 45+ years), ethnicity (White British, all other ethnic categories); Down syndrome (yes, no); being autistic (professional diagnosis/self-identification, all other categories); living situation 1 (living alone/with a partner, living with family, living with other people with intellectual disabilities); living situation 2 (living with support staff coming into the person's home, living without support staff coming into the person's home); label of Profound and Multiple Learning Disabilities (yes, no—Cohort 2 only).

**TABLE 3** Physical health.

	Cohort 1 (Wave 4 n = 358)	Cohort 2 (Wave 4 n = 192)
Does the person with learning disabilities have a health condition that makes them/you worry about having coronavirus?		
Wave 1—Yes	172 (53.9%)	120 (68.2%)
Wave 2—Yes	133 (43.6%)	127 (77.4%)
How is the person's health today?		
Wave 1		
Good	191 (59.5%)	80 (48.2%)
OK	113 (35.2%)	66 (39.8%)
Not very good	15 (4.7%)	20 (12.0%)
Wave 2		
Good	205 (61.9%)	80 (51.3%)
OK	99 (29.9%)	59 (37.8%)
Not very good	25 (7.6%)	17 (10.9%)
Wave 3		
Good	221 (65.4%)	82 (48.0%)
OK	99 (29.3%)	60 (35.1%)
Not very good	18 (5.3%)	29 (17.0%)
Wave 4		
Good	201 (56.5%)	97 (51.3%)
OK	127 (35.7%)	71 (37.6%)
Not very good	27 (7.6%)	21 (11.1%)
Health problems have got worse or have had new health problems (not coronavirus) in the last 4 weeks		
Wave 2	82 (24.8%)	47 (28.7%)
Wave 3	62 (18.2%)	49 (28.2%)
Wave 4	86 (24.0%)	49 (25.5%)
It is difficult to get medicines (of those with prescribed medicines)		
Wave 1	5 (2.0%)	0 (0.0%)
Wave 2	3 (1.2%)	1 (0.7%)
Wave 3	0 (0.0%)	0 (0.0%)
Wave 4	33 (11.7%)	35 (23.0%)

The health-related variables used in these analyses were: have had coronavirus (yes, no); current health (good, OK/not very good); difficulty getting medications (yes, no), have had an annual health check in 2022 (yes, no); have had contact with GP in the last 4 weeks (yes, no).

Full details of all the statistical tests conducted are available as supporting information (Supporting Information S1: Appendix Tables 1 and 2)—only those where there were statistically significant differences are reported in the main text.

TABLE 4 Access to health services.

	Cohort 1 (Wave 4 n = 358)	Cohort 2 (Wave 4 n = 192)
Cancellation of planned medical test		
Wave 1—since start of first lockdown March 2020	74 (23.1%)	43 (24.4%)
Wave 2—in last 4 weeks	15 (4.5%)	5 (3.0%)
Wave 3—in last 4 weeks	8 (2.3%)	13 (7.5%)
Wave 4—in last 4 weeks	13 (3.6%)	14 (7.3%)
Cancellation of planned medical operation		
Wave 1—since start of first lockdown March 2020	15 (4.7%)	5 (2.8%)
Wave 2—in last 4 weeks	3 (0.9%)	0 (0.0%)
Wave 3—in last 4 weeks	1 (0.3%)	2 (1.1%)
Wave 4—in last 4 weeks	3 (0.8%)	2 (1.0%)
Cancellation of planned hospital outpatient appointment		
Wave 1—since start of first lockdown March 2020	73 (22.7%)	64 (36.4%)
Wave 2—in last 4 weeks	17 (5.1%)	7 (4.3%)
Wave 3—in last 4 weeks	9 (2.6%)	17 (9.8%)
Wave 4—in last 4 weeks	15 (4.2%)	16 (8.3%)
Do you normally have an annual check?		
Wave 1—Yes	231 (72.0%)	n/a
Wave 2—Yes	225 (68.0%)	n/a
Wave 3—Yes	221 (65.4%)	n/a
Wave 4—Yes	248 (69.7%)	n/a
Have you had an annual health check...		
Wave 1—since the start of the first lockdown in March 2020		
Yes—in person	59 (18.3%)	22 (12.5%)
Yes—by video or phone call	33 (10.3%)	30 (17.0%)
Wave 2—since the start of 2021		
Yes—in person	41 (12.4%)	14 (8.5%)
Yes—by video or phone call	33 (10.0%)	19 (11.6%)
Wave 3—since the start of 2021		
Yes—in person	53 (15.5%)	22 (12.6%)
Yes—by video or phone call	28 (8.2%)	26 (14.9%)
Wave 4—since the start of 2022		
Yes—in person	112 (31.3%)	56 (29.2%)
Yes—by video or phone call	17 (4.8%)	16 (8.3%)
Contact with GP		
Wave 1—used to see GP regularly before the first lockdown in March 2020		
Yes	150 (46.7%)	77 (43.8%)

TABLE 4 (Continued)

	Cohort 1 (Wave 4 n = 358)	Cohort 2 (Wave 4 n = 192)
Wave 1—contact with GP since the start of the first lockdown in March 2020 (percentage of those who used to see GP regularly)		
The same/more	15 (10.0%)	18 (23.4%)
Not as much	79 (52.7%)	21 (27.3%)
Not at all	55 (36.7%)	37 (48.1%)
Wave 2—contact with GP in last 4 weeks (percentage of all people in Wave 2)		
Yes—in person	45 (13.6%)	13 (7.9%)
Yes—by phone/video link	71 (21.5%)	42 (25.6%)
No	233 (70.4%)	100 (61.0%)
Wave 3—contact with GP in last 4 weeks (percentage of all people in Wave 3)		
Yes—in person	49 (14.4%)	20 (11.5%)
Yes—by phone/video link	77 (22.6%)	38 (21.8%)
No	226 (66.3%)	112 (64.4%)
Wave 4—contact with GP in last 4 weeks (percentage of all people in Wave 3)		
Yes—in person	83 (23.2%)	28 (14.6%)
Yes—by phone/video link	45 (12.6%)	25 (13.0%)
No	237 (66.2%)	120 (62.5%)
Contact with community nurse (learning disability nurse or psychiatric nurse)		
Wave 1—used to see nurse regularly before the first lockdown in March 2020		
Yes	65 (20.2%)	59 (33.5%)
Wave 1—contact with nurse since the start of the first lockdown in March 2020 (percentage of those who used to see nurse regularly)		
The same/more	16 (24.7%)	17 (28.8%)
Not as much	28 (43.1%)	10 (16.9%)
Not at all	19 (29.2%)	31 (52.5%)
Wave 2—contact with nurse in last 4 weeks (percentage of all people in Wave 2)		
Yes—in person	31 (9.4%)	20 (12.2%)
Yes—by phone/video link	22 (6.6%)	18 (11.0%)
No	284 (85.8%)	117 (71.3%)
Wave 3—contact with nurse in last 4 weeks (percentage of all people in Wave 3)		
Yes—in person	33 (9.7%)	31 (17.8%)
Yes—by phone/video link	14 (4.1%)	18 (10.3%)
No	296 (86.8%)	127 (73.0%)
Wave 4—contact with nurse in last 4 weeks (percentage of all people in Wave 3)		
Yes—in person	36 (10.1%)	24 (12.5%)

TABLE 4 (Continued)

	Cohort 1 (Wave 4 n = 358)	Cohort 2 (Wave 4 n = 192)
Yes—by phone/video link	9 (2.5%)	13 (6.8%)
No	313 (87.4%)	155 (80.7%)
Contact with speech and language therapist, occupational therapist or physiotherapist		
Wave 1—used to see therapist regularly before the first lockdown in March 2020		
Yes	54 (16.8%)	65 (36.9%)
Wave 1—contact with therapist since the start of the first lockdown in March 2020 (percentage of those who used to see therapist regularly)		
The same/more	9 (16.7%)	8 (12.3%)
Not as much	10 (18.5%)	18 (27.7%)
Not at all	34 (63.0%)	38 (58.5%)
Wave 2—contact with therapist in last 4 weeks (percentage of all people in Wave 2)		
Yes—in person	17 (5.1%)	27 (16.5%)
Yes—by phone/video link	17 (5.1%)	13 (7.9%)
No	301 (90.9%)	114 (69.5%)
Wave 3—contact with therapist in last 4 weeks (percentage of all people in Wave 3)		
Yes—in person	21 (6.2%)	33 (19.0%)
Yes—by phone/video link	8 (2.3%)	12 (6.9%)
No	309 (90.6%)	128 (73.6%)
Wave 4—contact with therapist in last 4 weeks (percentage of all people in Wave 3)		
Yes—in person	27 (7.5%)	40 (20.8%)
Yes—by phone/video link	3 (0.8%)	7 (3.6%)
No	327 (91.3%)	140 (72.9%)

### 3 | RESULTS

COVID-19 (see Table 2). In Cohort 1, from Waves 1–3 between 6.9% and 8.9% of people reported having had COVID-19 at some point; at Wave 4, 61.2% of people reported having had COVID-19. The proportion of people who had had COVID-19 who had been hospitalised as a result reduced over time, from 22.7% of people at Wave 1 to 4.1% of people at Wave 4. In Cohort 2, from Waves 1–2 between 9.1% and 10.9% of people were reported to have had COVID-19 at some point; at Wave 4, this was 66.1% of people. The proportion of people who had had COVID-19 and been hospitalised as a result was low at all time points (5.9% at Wave 1 to 1.6% at Wave 4).

Younger people in Cohort 1 (aged 16–44) were more likely than older people (aged 45+) to have had COVID-19 by Wave 4 (Fisher's

$p < 0.001$ ). People in Cohort 1 living alone/with a partner were less likely to have had COVID-19 by Wave 4 than people living with family or with other people with learning disabilities ( $\chi^2 = 10.12$ ,  $df = 2$ ,  $p = 0.006$ ). There were no statistically significant differences for Cohort 2.

In Cohort 1, from Wave 2 onwards, over 90% of people had had at least one dose of the COVID-19 vaccine, reaching 97.2% of people by Wave 4. At Wave 4, most of those who had been vaccinated had received three or four doses of the COVID-19 vaccine (295 people; 85.2% of those vaccinated). In Cohort 2, from Wave 2 onwards, over 90% of people had had at least one dose of the COVID-19 vaccine, reaching 95.3% of people by Wave 4. At Wave 4, most of those who had been vaccinated had received three or four doses of the COVID-19 vaccine (155 people; 84.7%).

At Wave 1, 18.4% of people in Cohort 1 reported that they were 'shielding' to keep safe from COVID-19; this had reduced to one person (0.3%) by Wave 4. At Wave 1, 49.4% of people in Cohort 2 were reported to be shielding to keep safe from COVID-19; this had reduced to four people (2.1%) by Wave 4.

Physical health (see Table 3). More people in Cohort 1 reported their current health to be good at Wave 3 (65.4% good) compared to Wave 1 (59.5% good), although by Wave 4 self-reported current health was poorer than at Wave 1 (56.5% good). For Cohort 2, people's current health as reported by a family carer or support worker was fairly consistent across all four waves, with 49.0% to 51.3% reported to have good health at each time point.

For people in Cohort 1 at Wave 4, there was a difference in current self-reported health according to living situation ( $\chi^2 = 17.99$ ,  $df = 2$ ,  $p < 0.001$ ); 68% of people living with family reported being in good health, compared to 56% of people living with other people with learning disabilities and 42.6% of people living alone/with a partner. For people in Cohort 2, there was a difference in terms of PMLD (Fisher's exact  $p = 0.006$ )—40.5% of people with PMLD were reported to be in good health at Wave 4, compared to 62.2% of people without PMLD in Cohort 2.

The number of people in Cohort 1 reporting that their health had worsened or they had new (non-COVID) health conditions in the 4 weeks before being interviewed was substantial at Wave 2 (24.8%), Wave 3 (18.2%) and Wave 4 (24.0%). For Cohort 2, the proportion of people whose health was reported to have worsened in the 4 weeks before being surveyed was fairly consistent over time, from 28.7% of people at Wave 2 to 25.5% of people at Wave 4.

For Cohort 1, there was a difference in worsening health by broad ethnicity categories (Fisher's  $p \leq 0.001$ ), with 21.8% of people in White British ethnic groups and 50% of people in any other ethnic group reporting that their health had worsened in the 4 weeks before Wave 4 interviews. For Cohort 2, there was a difference in worsening health by PMLD (Fisher's  $p = 0.009$ ); the health of 36.6% of people with PMLD was reported to have worsened in the 4 weeks before Wave 4 surveys, compared to 18.0% of people without PMLD in Cohort 2.



At each wave, 76.6%–79.1% of people in Cohort 1 reported that they were regularly taking medications. At Waves 1–3, 2% or fewer of people reported having difficulty getting their medicines. At Wave 4 11.7% of people in Cohort 1 reported having difficulty getting their medicines. At each wave, 79.2%–82.2% of people in Cohort 2 were reported to be regularly taking medications. At Waves 1–3, fewer than 1% of people were reported to have difficulty getting their medicines. At Wave 4, 23.0% of people in Cohort 2 were reported to have difficulty getting their medicines.

There was a difference across countries in the proportions of people in Cohort 1 reporting difficulty in getting their medicines at Wave 4 ( $\chi^2 = 20.91$ ,  $df = 3$ ,  $p < 0.001$ ); 24.3% of people in England reported this difficulty, compared to 0% of people in Northern Ireland, 4.5% of people in Scotland and 13.8% of people in Wales. There were no differences by demographic factors in the proportions of people in Cohort 2 having difficulty getting medicines.

#### 4 | ACCESS TO HEALTH SERVICES (SEE TABLE 4)

The proportion of people in Cohort 1 with cancelled medical tests, operations and hospital outpatient appointments was lower at Wave 3 (2.3%; 0.3%; 2.6%) than at Wave 2 (4.5%; 0.9%; 5.1%) and Wave 4 (3.6%; 0.8%; 4.2%). For people in Cohort 2, the proportion of people with cancelled medical tests and hospital outpatient appointments was lower at Wave 2 (3.0%; 2.8%; 0.0%) than at Wave 3 (7.5%; 1.1%; 9.8%) and Wave 4 (7.3%; 1.0%; 8.3%).

For the questions on access to health services, different question and response formats were used at different time points, making statistical comparisons impossible.

Across all four waves, a consistent 65%–72% of people in Cohort 1 reported that they usually had an annual health check. At Wave 4, 31.3% of people reported having an annual health check in person and 4.8% reported having an annual health check by phone/video link from the start of 2022 to the Wave 4 interviews in October/November 2022. While trends over time are difficult to interpret, from Wave 1 to Wave 4 the proportion of annual health checks conducted in person has increased. For people in Cohort 2, at Wave 4 29.2% of people were reported to have had an annual health check in person and 8.3% were reported to have had an annual health check by phone/video link from the start of 2022 to the Wave 4 surveys in October/November 2022. While trends over time are difficult to interpret, from Wave 1 to Wave 4, the proportion of annual health checks conducted in person has increased.

There were differences across countries in terms of the proportion of people in Cohort 1 who had had an annual health check in 2022 ( $\chi^2 = 20.23$ ,  $df = 3$ ,  $p < 0.001$ ); 52.7% of people in England, 19% of people in Northern Ireland, 33.7% of people in Scotland and 31.9% of people in Wales had had an annual health check. There were also differences across countries in terms of the proportion of people in Cohort 2 who had had an annual health check in 2022 ( $\chi^2 = 42.58$ ,  $df = 3$ ,  $p < 0.001$ ); 60.0% of people in England,

45.0% of people in Northern Ireland, 7.1% of people in Scotland and 25.0% of people in Wales had had an annual health check. There was a difference by PMLD (Fisher's  $p < 0.001$ ); 22.1% of people with PMLD had had an annual check in 2022 up to Wave 4, compared to 48.9% of people without PMLD in Cohort 2.

In terms of access to GP services, 46.7% of people in Cohort 1 at Wave 1 reported that they used to regularly see a GP before the first COVID-19 lockdown. For people in Cohort 1, 23.2% of people had contact with their GP in person and 12.6% had contact with their GP by phone/video link in the 4 weeks before Wave 4 interviews. The overall proportion of people in Cohort 1 in contact with their GP was similar at Waves 2–4, although the proportion of people in contact with their GP in person rather than by phone/video link was higher at Wave 4.

At Wave 4, 93 people (26.0%) in Cohort 1 saw the same doctor at their GP practice, with 241 people (67.3%) seeing different doctors. People in Cohort 1 most commonly preferred to talk to their GP face to face (312 people; 87.2%).

At Wave 4, 150 people in Cohort 1 (41.9%) reported it was easy for them to contact their GP when they needed to. A further 99 people (27.7%) had someone else to contact the GP for them, and 107 people (29.9%) said it was not easy for them to contact their GP. People most commonly reported the following difficulties: not being able to get through on the phone (76 people; 21.2%); no appointments being available (59 people; 16.5%); and the phone appointment booking system being too complicated (31 people; 8.7%).

In terms of access to GP services, 43.8% of people in Cohort 2 at Wave 1 were reported to regularly see a GP before the first COVID-19 lockdown. For people in Cohort 2, 14.6% of people had contact with their GP in person and 13.0% had contact with their GP by phone/video link in the 4 weeks before Wave 4 surveys. The overall proportion of people in Cohort 2 in contact with their GP was similar at Waves 2–4, although the proportion of people in contact with their GP in person rather than by phone/video link was higher at Wave 4. At Wave 4, 41 people (21.4%) in Cohort 2 saw the same doctor at their GP practice, with 130 people (67.7%) seeing different doctors. Family carers/support workers of people in Cohort 2 most commonly preferred to talk to the GP face to face (100 people; 52.1%), although substantial numbers preferred phone or video call (43 people; 22.4%) or said it would depend on the issue (48 people; 25.0%).

At Wave 4, 89 family carers/support workers of people in Cohort 2 (46.4%) reported it was easy for them to contact the person's GP when they needed to. A further 26 people (13.5%) said that they did not contact the GP for the person, and 74 people (38.5%) said it was not easy for them to contact their GP. People most commonly reported the following difficulties: not being able to get through on the phone (51 people; 26.6%); no appointments being available (48 people; 25.0%); not being able to go into the surgery to book an appointment (19 people; 9.9%); and the phone appointment booking system being too complicated (14 people; 7.3%).

For people in Cohort 1, there was a difference by living situation ( $\chi^2 = 29.69$ ,  $df = 2$ ,  $p < 0.001$ ) in the proportion of people being in

contact with their GP in the last 4 weeks; 17.7% of people living with their family were in contact with a GP in the 4 weeks before Wave 4 interviews, compared to 46.9% of people living alone/with a partner and 42.7% of people living with other people with intellectual disabilities. There were no statistically significant differences for people in Cohort 2.

In terms of access to community nurses, 20.2% of people in Cohort 1 at Wave 1 reported that they used to regularly see a community nurse before the first COVID-19 lockdown. For people in Cohort 1, in the 4 weeks before Wave 4 interviews, 10.1% of people had contact with a community nurse in person and 2.5% had contact with a community nurse by phone/video link. The overall proportion of people in Cohort 1 in contact with a community nurse was similar at Waves 2–4, although the proportion of people in contact with a community nurse in person rather than by phone/video link was higher at Wave 4.

For people in Cohort 2, 33.5% of people at Wave 1 were reported to have regularly seen a community nurse before the first COVID-19 lockdown. In the 4 weeks before Wave 4 interviews, 12.5% of people had contact with a community nurse in person and 6.8% had contact with a community nurse by phone/video link. The overall proportion of people in Cohort 2 in contact with a community nurse was higher at Wave 2 and Wave 3 than at Wave 4, although the proportion of people in contact with a community nurse in person rather than by phone/video link increased over time.

In terms of access to speech and language therapists, occupational therapists and physiotherapists, 16.8% of people in Cohort 1 at Wave 1 reported that they used to regularly see a therapist before the first COVID-19 lockdown. For people in Cohort 1, in the 4 weeks before Wave 4 interviews 7.5% of people had contact with a therapist in person and 0.8% had contact with a therapist by phone/video link. The overall proportion of people in Cohort 1 in contact with a therapist was similar at Waves 2–4, although the proportion of people in contact with a therapist in person rather than by phone/video link was higher at Wave 4.

For people in Cohort 2, 36.9% of people were reported to have regularly seen a therapist before the first COVID-19 lockdown. For people in Cohort 2, 20.8% of people had contact with a therapist in person and 3.6% had contact with a therapist by phone/video link in the 4 weeks before Wave 4 interviews. The overall proportion of people in Cohort 2 in contact with a therapist was similar at Waves 2–4, although the proportion of people in contact with a therapist in person rather than by phone/video link increased over time.

## 5 | DISCUSSION

Findings from this study show clearly that the multiple and severe disruptions to health services (with the exception of COVID-19 vaccination) that people with learning disabilities experienced through the COVID-19 pandemic (Keenan & Doody, 2023; Taggart et al., 2022) have continued and in some respects worsened in the United Kingdom in the 'postpandemic' phase, rather than returning to

prepandemic levels or health services compensating for this disruption. People with learning disabilities' physical health has shown little to no improvement since the national UK lockdown in early 2021, with people with greater health needs (particularly those with profound and multiple learning disabilities) showing consistently poorer health and reduced access to health services 'postpandemic'. When interpreting the findings from this paper, it is important to note the limitations of the study. First, of necessity, recruitment of participants was rapid and to an extent opportunistic, with participants self-describing or describing people they were caring for/supporting as a person with learning disabilities. Second, to meet the aim of the project as a whole (see Flynn, Bailey, et al., 2021) to provide rapid, relevant feedback to policymakers and other organisations questions often changed over time, limiting our capacity to analyse some changes over time. Third, because the project was designed after the COVID-19 pandemic started, pre-COVID data were not available, and participants' recall of access to health services pre-COVID may be subject to recall bias.

**COVID-19:** Throughout the COVID-19 pandemic from Wave 1 to Wave 3, relatively low proportions of people in this study were reported to have had COVID-19. By Wave 4, the proportion of people who had had COVID-19 sharply increased, from around 10% of people at Wave 3 to over 60% of people at Wave 4. This compares to figures for the general population of 51.5% for Scotland to 72.2% for Northern Ireland up to the end of February 2022 (British Medical Association, 2023). By Wave 4, amongst Cohort 1, people with learning disabilities living alone/with a partner were less likely to have had COVID-19 than people living either with family or with other people with learning disabilities, possibly reflecting other research showing that living with large numbers of other people was the biggest risk factor for COVID-19 mortality amongst people with learning disabilities (Office for National Statistics, 2021).

Evidence from other UK studies has shown that people with learning disabilities were more likely to be hospitalised and to die from COVID-19 at earlier ages in the first COVID-19 wave (e.g. Henderson et al., 2022; Office for National Statistics, 2021; Sosenko et al., 2023), and that the magnitude of this increased risk may be reducing over time as people started getting COVID-19 vaccines (Sosenko et al., 2023). In this project, 95%–97% of people had received at least one dose of the COVID-19 vaccine by Wave 4 (compared to 94% of the general population in the United Kingdom by August 2022; Office for National Statistics, 2023a).

Several issues arise from these data. First, it is still unclear what the long-term health effects of COVID-19 infection (and re-infection) are although there may be increased risks of a range of health problems (Bowe et al., 2022; Lopez-Leon et al., 2021). Second, it is important that people with learning disabilities continue to be encouraged to take up COVID-19 vaccine boosters as the effectiveness of vaccines may wane over time. Third, although the vast majority of people with learning disabilities have had multiple COVID-19 vaccine doses, there is evidence that take-up has been lower amongst younger adults and adults from minority ethnic communities (OpenSAFELY, 2022) and it is unclear how proactive

efforts will be to increase COVID-19 vaccine coverage amongst these groups. Fourth, other findings from the wider project of which this paper is a part (Flynn et al., 2021a, 2021b) have consistently shown that for some people with learning disabilities a COVID-19 vaccine is not possible, particularly amongst people who are most likely to be at risk if infected with COVID-19. For people with learning disabilities in this position and for those supporting them, in the absence of public health protections, there is currently no support or consideration of how people can exercise their choice to live fulfilling lives in conditions of relative safety.

**Health status:** Overall, people's self-reported or carer-reported current health showed fluctuations over time from Wave 1 (in a national lockdown) to Wave 4 (over a year 'post-COVID'). The position for both cohorts was similar at Wave 4 to how it was at Wave 1, with just over half of people reported to be in good health. Although using a different indicator of physical health, the health of the UK general population is reported to have slightly improved from 2020 to 2021 (Office for National Statistics, 2023b). From Wave 2 to Wave 4, around a quarter of people in both cohorts were reported to have had new or worsening (non-COVID) health problems in the 4 weeks before each interview/survey. At the very least, this suggests that people's overall health has not improved from the time of a national lockdown to more than 1 year 'post-COVID', with people consistently developing new health problems or their existing problems worsening. Possible reasons that have been suggested for this in other international literature (see Keenan & Doody, 2023; Taggart et al., 2022) have included the health impact of not receiving continuous therapy support (e.g. physiotherapy), the impact of reduced physical activity, including outdoor activity, the cumulative side effects of medication regimes that have not been reviewed, cancelled and postponed medical procedures and less proactive contact with a range of health services (e.g. GP services). Given the high and early developing rates of multiple health conditions amongst people with learning disabilities generally (Kinnear et al., 2018), in the absence of proactive health support, it is to be expected that health status would worsen over time.

**Access to medications and health services:** During the pandemic, including at times of lockdowns and considerable restrictions (Waves 1–3), very few people with learning disabilities in either cohort reported difficulties in getting their medications, with difficulties possibly lower than for the general UK population at this point (Maddock et al., 2022). However, by Wave 4, over 10% of people in Cohort 1 and over 20% of people in Cohort 2 (with likely greater health needs as a group) were having difficulty getting their medications, particularly in England. Over a similar time period to Wave 4, between 3% and 5% of adults in Great Britain reported shortages of medicine (Office for National Statistics, 2023d).

This lack of improvement, or in some cases worsening, of access to health services 'postpandemic' is evident across all the health services we asked about in the project. Overall, at Wave 4, more people with learning disabilities were having more planned medical tests and hospital outpatient appointments cancelled than at Wave 2,

with little evidence of increases over time in annual health checks (which were more common in England), or contact with GPs, community nurses or a range of therapists. Most people did not regularly see the same GP, and many people and family carers/support workers were finding it difficult to get a GP appointment by Wave 4. However, by Wave 4, most contact had returned to being face to face rather than by phone/video, which people most commonly preferred. Although exactly comparable information is not available, figures for GP access may, if anything, be lower than for the general population (Office for National Statistics, 2023c) and are certainly lower at Wave 4 than the proportion of people reported to be in regular contact with their GP before the pandemic.

As the COVID-19 pandemic has continued and moved into a largely postpandemic phase in terms of public health protections and service responses, both people with learning disabilities and family carers in the United Kingdom have continued to report feeling exhausted, forgotten and abandoned (Scherer et al., 2023). Radically improving health services for people with learning disabilities, alongside improvements to other social care services and supports that have also not returned to likely prepandemic levels (Hatton et al., 2023) should be an urgent priority.

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## CORONAVIRUS AND PEOPLE WITH LEARNING DISABILITIES STUDY TEAM

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## CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

## ETHICS STATEMENT

Research ethics approval was sought and obtained from the Manchester Metropolitan University Faculty of Health, Psychology and Social Care Faculty Research Ethics Committee for all four waves of data collection.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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