



# **Coronavirus and People with Learning Disabilities Study**

## **Wave 1 Results March 2021**

### **Full Report**

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# Chapter 1: Introduction

## **1.1. Background and rationale for this study**

There are approximately 1.5 million people with learning (intellectual) disabilities across the UK<sup>1</sup>. Recent data indicate that people with learning disabilities are more likely to contract COVID-19, have a more severe case of COVID-19, and are three times more likely than people without learning disabilities to die from COVID-19<sup>2</sup>. People with learning disabilities are a very diverse group; while some people need 24-hour support others have limited or no social care support. Inequalities in health, wellbeing, social isolation, employment and poverty that existed before COVID-19, along with separation from family and friends and changes to routines, may have been exacerbated during the COVID-19 pandemic.

User-led organisations, families and social care support providers have reported multiple challenges associated with social restrictions, maintaining infection control, and the provision of social care support to people and families. There have also been geographical variations in social and health care services' responses to COVID-19; in terms of both how and whether people receive support. We have written about these issues in our first two brief reports from the project<sup>3</sup>.

Current large-scale surveys, with their general population remit, are using methods (e.g., online surveys) likely to exclude most people with learning disabilities. Even when these surveys are nationally representative, they will not include sufficient numbers of people with learning disabilities to allow for meaningful analysis across different parts of the UK. They also do not have the flexibility to ask questions of specific relevance to people with learning disabilities. These larger surveys are typically being carried out without the specific resources and expertise that would enable the direct interview methods, with adapted questions and trained interviewers, needed for people with learning disabilities to participate.

The project reported here uses these direct interview methods and is designed to systematically and responsively track the experiences of adults with learning disabilities through the COVID-19 pandemic over time across the UK, and investigate swiftly actionable factors associated with better outcomes.

This project is designed to have direct input from, and relevance to, people with learning disabilities and families, policy-makers, service commissioners, and providers of services across the UK throughout the 12-month project. There are three 'Waves' of data collection to capture differences and changes over time during the COVID-19 pandemic from the same cohorts of people. There are two cohorts of

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<sup>1</sup> Mencap. (2021). *How common is learning disability?* Available at: <https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/how-common-learning-disability> (Accessed on 9th March 2021)

<sup>2</sup> Henderson, A., Fleming, M., Cooper, S. A., Pell, J., Melville, C., MacKay, D., ... & Kinnear, D. (2021). COVID-19 infection and outcomes in a population-based cohort of 17,173 adults with intellectual disabilities compared with the general population. *medRxiv*

<sup>3</sup> [https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability/resultsoctober20/coronavirus\\_and\\_people\\_with\\_learning\\_disabilities\\_-\\_easy\\_read\\_v2.pdf](https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability/resultsoctober20/coronavirus_and_people_with_learning_disabilities_-_easy_read_v2.pdf)  
[https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability/resultsoctober20/covid-19\\_key\\_issues\\_brief\\_report\\_v2\\_12.11.20.pdf](https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability/resultsoctober20/covid-19_key_issues_brief_report_v2_12.11.20.pdf)  
[https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability/resultsganuary21/coronavirus\\_and\\_people\\_with\\_learning\\_disabilities\\_emerging\\_issues\\_report\\_easy\\_read\\_v2.pdf](https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability/resultsganuary21/coronavirus_and_people_with_learning_disabilities_emerging_issues_report_easy_read_v2.pdf)  
[https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability/resultsganuary21/covid-19\\_key\\_issues\\_brief\\_report\\_25.2.21.pdf](https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability/resultsganuary21/covid-19_key_issues_brief_report_25.2.21.pdf) (all accessed 19 March 2021)

participants: Cohort 1 are adults with learning disabilities who take part in an interview with a researcher, and Cohort 2 are family carers and support staff of adults with learning disabilities who could not take part in an interview themselves, including people with profound and multiple learning disabilities (PMLD).

The research focuses on three key questions:

1. What are the wellbeing, health, and social effects of the COVID-19 pandemic, including social restrictions and changes to how people are supported, on the lives of adults with learning disabilities across the UK over time?
2. What actionable factors are associated with better outcomes for different groups of people with learning disabilities?
3. What urgent issues concerning people with learning disabilities are emerging over time?

In this report, we will describe the main results of the first Wave of the Coronavirus and People with Learning Disabilities Study. This report is intended as a reference source, and additional technical reports of data for each country, summaries and accessible versions of the findings will be produced separately and made freely available.

## **1.2. Brief study methods**

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

We aimed to include 1,000 people with learning disabilities (Cohort 1) across the UK, and 500 family carers or paid support staff of people with learning disabilities who could not take part in an interview themselves (Cohort 2). This was broken down by country, with a target of interviewing 400 people with learning disabilities in England and 200 each in Northern Ireland, Scotland, and Wales. For the surveys with family carers or paid support staff, we aimed to receive responses from 200 people in England and 100 each in Northern Ireland, Scotland, and Wales.

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

The interview schedule and survey were designed in consultation with advisory groups of people with learning disabilities and family carers of people with profound and multiple learning disabilities (PMLD). We undertook this consultation in a number of steps:

1. We asked people with learning disabilities and family carers from across the UK about the issues that were important to them in October 2020, before we started developing the Wave 1 interview and survey
2. We asked advisory groups in each country to provide their feedback on the drafted interview and/or survey
3. We consulted further with advisory groups from across the UK for the interview and survey before we started data collection



4. We continue to routinely ask these advisory groups about urgent and emerging issues; this is particularly the case at the start of each Wave of survey development.

### **1.2.3. How did we find people?**

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 staff only) on the project website<sup>4</sup>.

### **1.2.4. How did we collect the data?**

Data were collected between December 2020 and February 2021.

#### 1.2.4.1. Cohort 1: Adults with learning disabilities

For Wave 1 of this study, we directly interviewed (via Zoom, telephone, Microsoft Teams, WhatsApp video call, Messenger video call, and FaceTime) 618 adults with mild/moderate learning disabilities across the UK (Cohort 1). Data were entered directly into Qualtrics™ during the interviews. Interviews were undertaken using the preferred digital platform or on the telephone for each participant. Three people preferred to self-complete an online version of the survey, and in these cases this was made available to them at their request. Thus the sample for Cohort 1 was 621 adults with learning disabilities.

Participants were also able to 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 were able to participate in their preferred way.

Interviews took, on average, 45 minutes to complete, and were usually completed in one sitting. Short breaks were offered during interviews when needed.

#### 1.2.4.2. Cohort 2: Family carers and paid support staff 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 (although we do not have direct information about these individuals' level of learning disability); a group with high support needs who were unlikely to be represented in any large-scale experience surveys. To gather data on this group, we surveyed their family carers or paid support staff using an online self-completion Qualtrics™ survey (Cohort 2).

In Cohort 2, participants were the family carers and paid support staff of 378 adults with learning disabilities.

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<sup>4</sup> <https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability/studyinformation/> (accessed 19 March 2021)

In Cohort 2, 83% of participants were family carers of an adult with learning disabilities and 15% of participants were paid support staff of an adult with learning disabilities. The remaining 3% of participants were other people who knew the adult with learning disabilities very well (e.g., a friend).

## **1.2.5. How did we analyse the data?**

### 1.2.5.1. Quantitative data

The analysis for Wave 1 was descriptive, with percentage estimates relating to the responses for individual survey items. Data from Cohort 1 and Cohort 2 were analysed separately and, where appropriate, descriptive comparisons have been made between the two cohorts. Statistically significant differences across groups (based on age above and below 45, and whether the person with learning disabilities lived with family or not) on percentage endorsement of items were derived from chi-square analysis; with resultant odds ratios reported as effect size estimates. This report only includes the findings from these comparisons where there were statistically significant differences.

It was also the case that some survey items related to sub-groups of people. If so, we report the number who completed the question alongside the percentage estimates. All analyses were conducted in SPSS v.27.

To aid interpretability, percentage estimates were rounded off to the nearest whole number. The sole exception to this was when percentage estimates were between (and exclusive of) 0% and 0.5%, in which case we used <1% to signify such instances.

### 1.2.5.2. Qualitative data

There were a series of open-ended questions asked of both cohorts. For Cohort 1, researchers conducting the interviews typed the responses into text boxes on Qualtrics™. For Cohort 2, participants typed their responses into the text boxes in the online survey.

Selected responses from open-ended questions for both cohorts in Wave 1 have been included in Boxes throughout the report to provide additional context to the descriptive data and to give more detail about the COVID-19-related experiences of participants in both cohorts. Included responses have been chosen to illustrate the overall responses made to the open-ended questions.

### 1.2.5.3. Comparisons with other national surveys

Where comparable data were available from other national surveys, we have included these in the report to compare with our study data. Where appropriate, throughout the report, we state the study/survey from which the data originated, describe the findings, and compare them to ours.

### **1.3. COVID-19 restrictions during data collection**

This sub-section summarises the COVID-19 restrictions that were in place in each UK country between December 2020 and February 2021, whilst we were collecting data for Wave 1 of this study. The restrictions are summarised in Table 1.1 below.

Table 1.1. A summary of COVID-19 restrictions in each UK country between December 2020 and February 2021

	<b>England</b>	<b>Northern Ireland</b>	<b>Scotland</b>	<b>Wales</b>
<b>December 2020</b>	Four tier system is in place throughout December  Restrictions are relaxed for Christmas Day	“Circuit breaker lockdown” until 11 <sup>th</sup> December  Restrictions are relaxed for Christmas Day  Full “lockdown” from 26 <sup>th</sup> December	Four tier system is in place throughout December  Travel to the rest of the UK is prohibited  Restrictions are relaxed for Christmas Day  Level four measures in place across Scotland from 26 <sup>th</sup> December	National restrictions in place in Wales throughout December  New full lockdown began from 20 December  Restrictions are relaxed for Christmas Day
<b>January 2021</b>	Full “lockdown” from 6 <sup>th</sup> January	Full “lockdown” throughout January	Full “lockdown” throughout January	Full “lockdown” throughout January
<b>February 2021</b>	Full “lockdown” throughout February	Full “lockdown” throughout February	Full “lockdown” throughout February	Full “lockdown” throughout February



## **Chapter 2: People with learning disabilities and the COVID-19 pandemic: Overall results from both cohorts**

## **2.1. Who took part?**

In Cohort 1, 621 people with learning disabilities and, in Cohort 2, 378 family carers or support staff of people with learning disabilities took part in the study. The total number of participants who were recruited in each country is shown in Figure 2.1 below, separated by cohort.

In the description below, we discuss the results from the two cohorts of the survey to bring a total picture of the people with learning disabilities who took part in interviews or who had a survey completed by someone who knew them well. Table 2.1 presents the demographic data separated by cohort. Information about the living circumstances of people with learning disabilities is presented in Table 2.2.

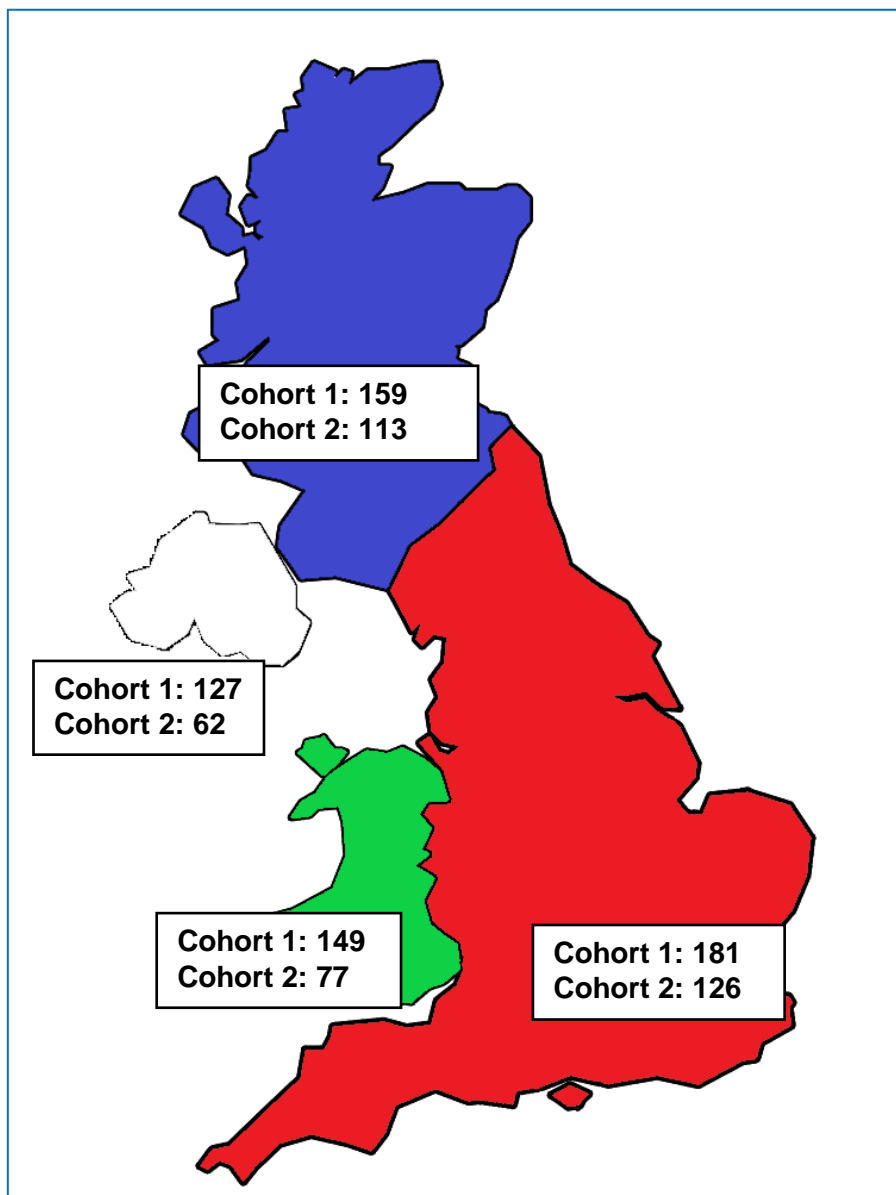


Figure 2.1. A map of the UK showing number of people who took part in the study in each country by cohort (5 people in Cohort 1 did not state which UK country they were from)



Table 2.1. Demographic data for the people with learning disabilities, separated by study cohort

	Cohort 1 (N = 621)	Cohort 2 (N = 378)
<b>Gender</b>		
Male	51%	55%
Female	48%	42%
Other	1%	3%
<b>Age</b>		
16-24	14%	31%
25-34	31%	32%
35-44	23%	18%
45-54	16%	11%
55-64	12%	6%
65+	4%	3%
<b>Ethnicity</b>		
Asian	1%	1%
Black	2%	0%
Mixed ethnic backgrounds	2%	3%
White	96%	93%
Other ethnic background	<1%	2%
<b>Marital status</b>		
Single	70%	
In relationship	22%	
Married/civil partnership	4%	
Divorced/Separated/Widowed	3%	
Other	1%	
<b>Where people live</b>		
Town	49%	46%
City	32%	30%
Village	19%	24%
<b>Relationship to person cared for</b>		
Family Carer		83%
Support Worker/Paid Carer		15%
Other e.g. friend		3%
<b>Does “PMLD” apply to the person with learning disabilities</b>		
Yes		44%
No		45%
Don't Know		11%
<b>Down syndrome</b>	11%	18%

NB. Where a table cell is left blank, this indicates that the option was not available in that survey. This applies throughout this report.

The number of men and women in both cohorts was broadly similar, and relatively even within each cohort. People with learning disabilities from Cohort 2 were generally younger than people with learning disabilities in Cohort 1, but there was a good spread of ages in both cohorts. Most people with learning disabilities were White, with very few people from ethnic minorities in either cohort at Wave 1.

Adults with Down syndrome were 4.4 times more likely to live with family than with others in Cohort 1 ( $p < .001$ ), and 2.3 times more likely in Cohort 2 ( $p = .01$ ). In Cohort 2, people living with their family were twice as likely to live in a city than a town or village, compared with people living elsewhere ( $p = .01$ ).

Table 2.2. Who people with learning disabilities live with

	Cohort 1	Cohort 2
<b>Who does the person with learning disabilities live with?</b>		
Live alone with no support from staff	8%	1%
Live alone with support staff coming into their home (supported accommodation)	23%	9%
Live with their partner with no support from staff	3%	
Live with their partner with support staff coming into their home	1%	
Live with family with no support from staff	35%	40%
Live with family with support staff coming into their home	5%	18%
Live in a Shared Lives arrangement	3%	2%
Live with other people with learning disabilities with no support from staff	1%	
Live with other people with learning disabilities with support staff coming into their home during the day	5%	
Live with other people with learning disabilities with support staff coming into their home during the day and night	17%	23%
Live in a secure placement		<1%
Live in a different type of home e.g. residential college		8%
<b>The person with learning disabilities looks after someone they live with (N = 423)</b>	12%	

The majority of people with learning disabilities in Cohort 1 lived alone (31%) or with their family (40%), either with or without support staff coming into their home. In Cohort 2, the majority of people with learning disabilities lived with their family (58%) with or without support staff coming into their home. Of the 50 people with learning disabilities who reported that they look after someone who they lived with, 46% said that they look after their parents, 14% look after their child/children, 12% look after their partner, and 28% said that they look after someone else who they live with.

Younger adults with learning disabilities (aged 44 or younger) were 7.5 times (Cohort 1;  $p < .001$ ) and 5.6 times (Cohort 2;  $p < .001$ ) more likely to live with their family than adults aged 45 and older.

## **2.2. COVID-19**

In this sub-section, we report the findings from questions in the interviews and surveys relating specifically to COVID-19. These are:

- whether it was easy to find good and accurate information about COVID-19,
- if people with learning disabilities knew what the rules were about COVID-19 and social distancing where they lived, and how they found out about changes to these rules,
- whether they had a health condition that made them worry about getting COVID-19,
- whether they had been tested for COVID-19,
- whether they, or anyone they knew, had had COVID-19,
- whether they had been hospitalised because of COVID-19 symptoms,
- whether they were, or had previously been, shielding (whether they had received an official shielding letter or not)
- about the NHS Test and Trace app (or country-specific equivalent),
- whether they had self-isolated,
- whether personal protective equipment (PPE) was being worn by their family carers or support staff,
- about wearing face masks/coverings,
- whether they knew someone who had died because of COVID-19, and
- about COVID-19 vaccinations.

### **2.2.1. Information and rules about COVID-19**

We asked participants in Cohort 1 whether it was easy to find good and accurate information about COVID-19. These data are found in Figure 2.2 below.

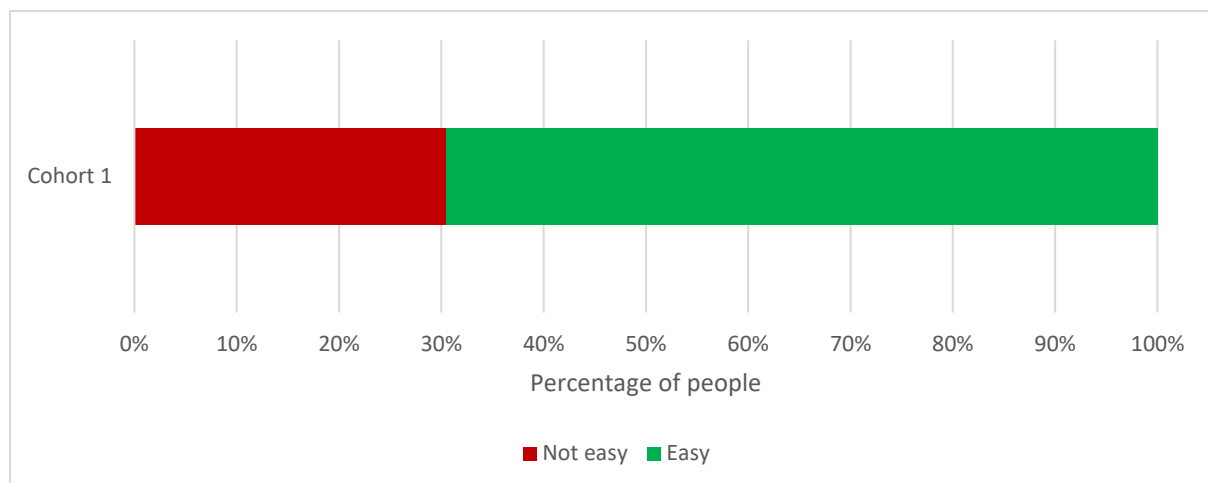


Figure 2.2. Has it been easy for you to find good information about COVID-19 that you understand? (Cohort 1 only)

Figure 2.2 shows that most people in Cohort 1 (70%) reported it was easy to find good information about COVID-19.

We also asked whether participants in Cohort 1 knew what the rules were about COVID-19 and social distancing where they lived. These rules differed between the four UK nations and throughout the period of data collection. We therefore asked about the rules in a general sense. The data are presented in Figure 2.3.

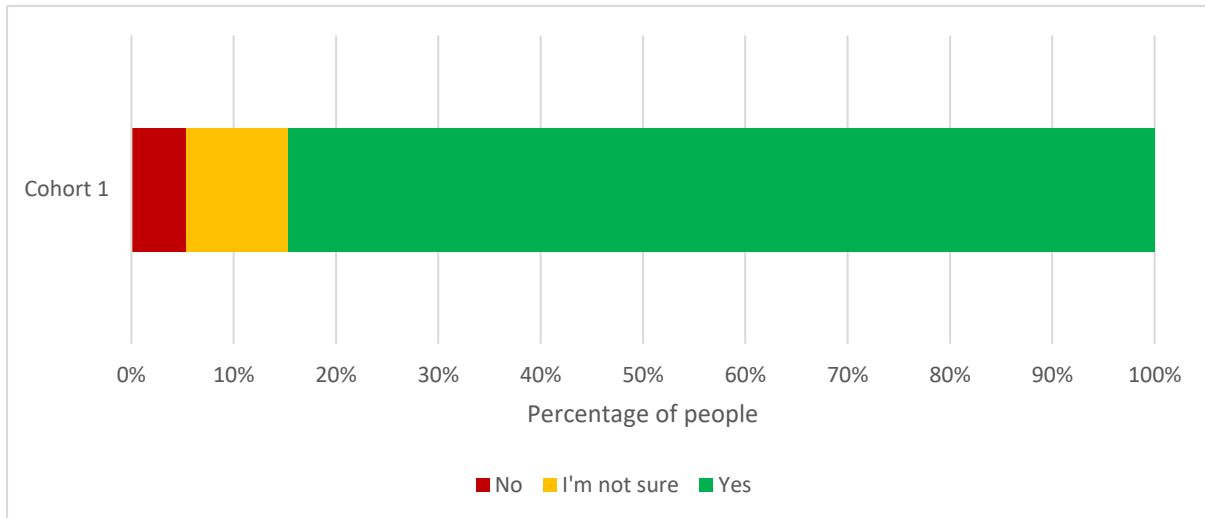


Figure 2.3. Do you know what the rules are now where you live about COVID-19 and social distancing? (Cohort 1 only)

Figure 2.3 indicates that the vast majority (85%) of people with learning disabilities in Cohort 1 reported that they understood the rules about COVID-19 and social distancing where they lived. As the rules were ever-changing, we asked participants about how they found out about changes to COVID-19 rules and information. Participants were asked to select all the ways they found information about COVID-19 rule changes. These data are presented in Figure 2.4.

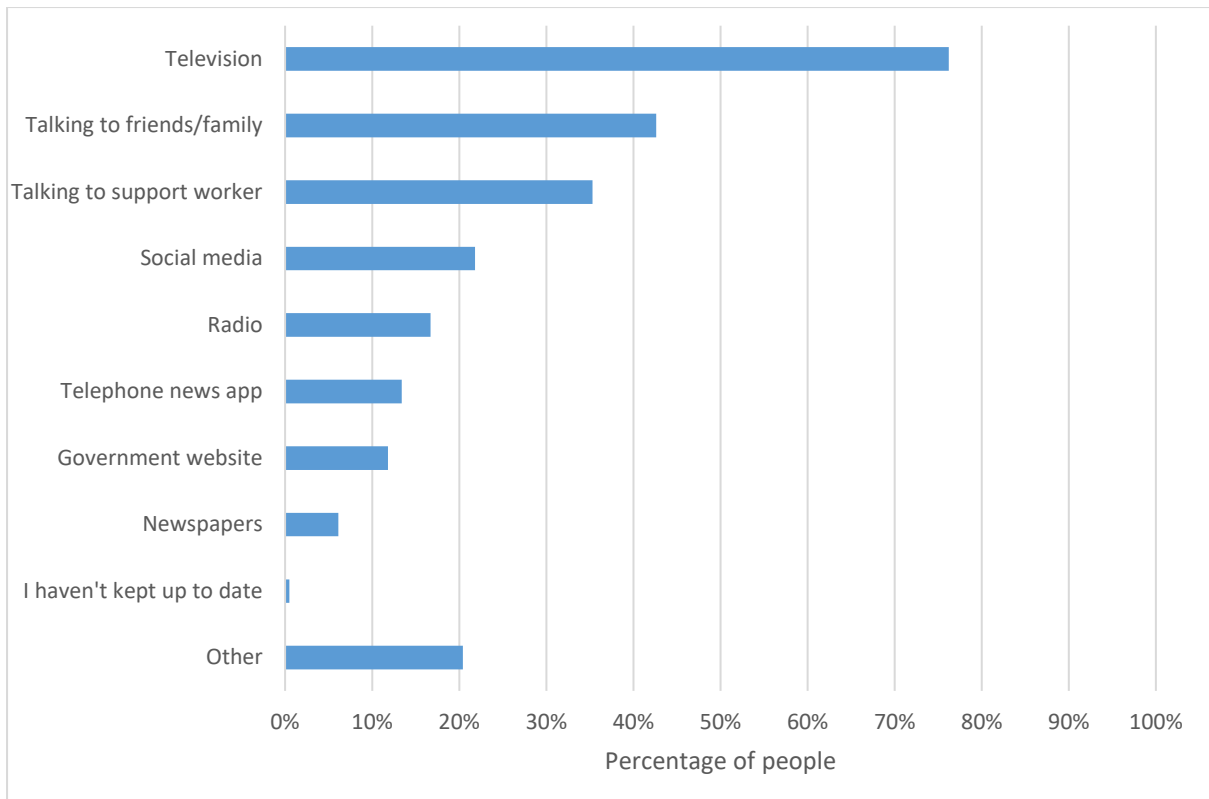


Figure 2.4. How do you find out about changes to COVID-19 rules/information? (Select all that apply) (Cohort 1 only)

The majority of people in Cohort 1 found out about changes to COVID-19 rules/information by watching the television (76%) or by talking to their friends and family (43%) or support workers (35%).

### 2.2.2. Health conditions, having COVID-19 and testing for COVID-19

We asked participants in both cohorts about whether they (Cohort 1) or the person they support/care for (Cohort 2) had a health condition that made them worry about catching COVID-19. The data from each cohort are displayed in Figures 2.5 and 2.6.



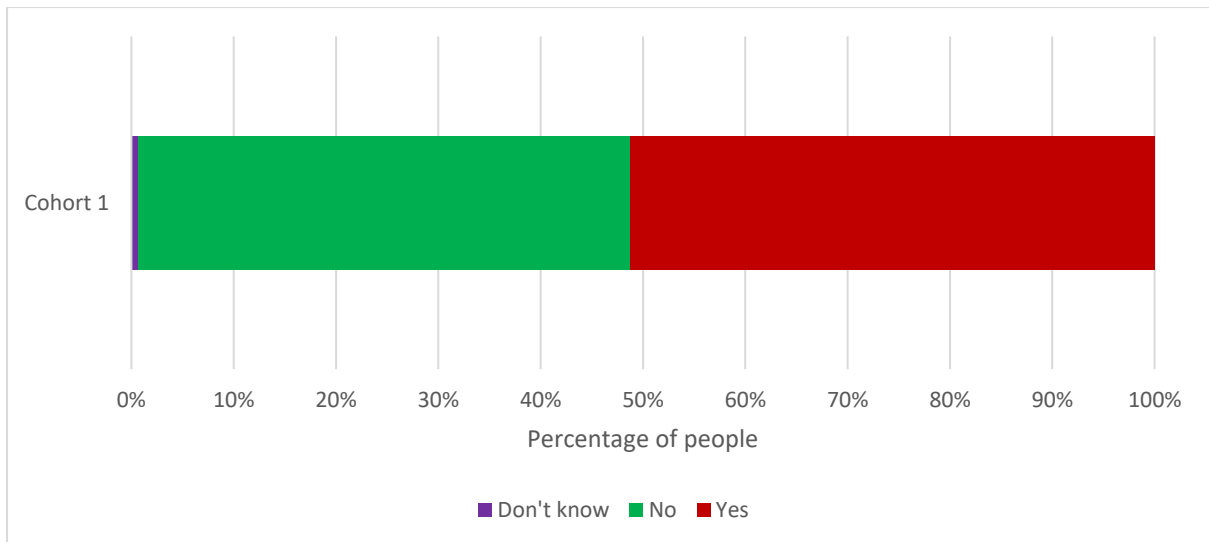


Figure 2.5. Do you have a health condition that makes you worry about having COVID-19? (Cohort 1 only)

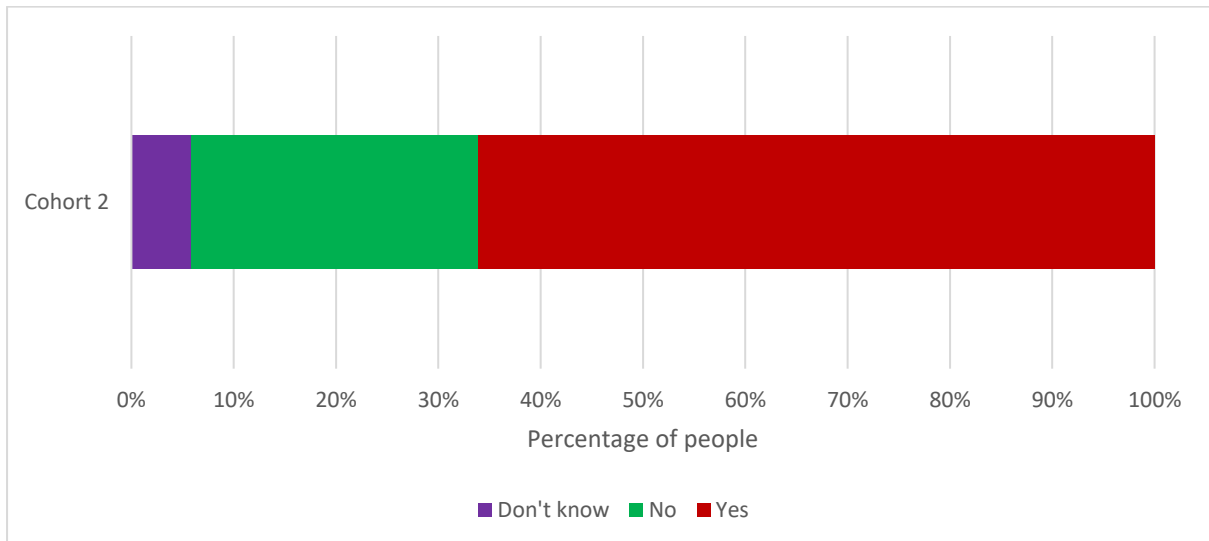


Figure 2.6. Does the person you support/care for have a health condition that makes you worry about them having COVID-19? (Cohort 2 only)

More people with learning disabilities in Cohort 2 had health conditions that were of concern if they had COVID-19 than in Cohort 1 (67% vs 51%). The most common health conditions for Cohort 1 were asthma and epilepsy. For Cohort 2, the most common health condition was epilepsy.

In Cohort 1, people with learning disabilities who were living with their family were 1.6 times less likely to have a health condition that made them worry about getting COVID-19 than people with learning disabilities who lived elsewhere ( $p = .02$ ).

We also asked whether people with learning disabilities had been tested for COVID-19. The number of people in both cohorts who had had a COVID-19 test, and the results of these tests, are displayed in Table 2.3. If there had been more than one

COVID-19 test, we asked participants to answer about the most recent one that the person with learning disabilities had had.

Table 2.3. Testing for COVID-19

	<b>Cohort 1</b>	<b>Cohort 2</b>
<b>Yes – positive result</b>	3%	7%
<b>Yes – negative result</b>	26%	28%
<b>Yes – unclear result</b>	1%	1%
<b>Yes – awaiting result</b>	1%	<1%
<b>No</b>	69%	62%
<b>Don't know</b>	<1%	1%

In both cohorts, of the 190 people in Cohort 1 and the 144 people in Cohort 2 to have a COVID-19 test, the vast majority were negative (85% and 79% respectively). Data for this question can be compared to a general population sample collected for the Understanding Society COVID-19 Survey<sup>5</sup>. In the Understanding Society survey in November 2020, of the 391 people surveyed, 78 people (20%) reported having a COVID-19 test, fewer than the 31%-37% reported in this study. Of these, 88% reported that this was negative, which is broadly comparable to both cohorts in our study. People with learning disabilities who were living with their family were 1.8 times less likely (Cohort 1;  $p = .02$ ) and 2.8 times less likely (Cohort 2;  $p < .001$ ) to have had a test for COVID-19 than were people with learning disabilities who lived elsewhere.

We also asked both cohorts about who they know who has had COVID-19. These questions related to the person with learning disabilities themselves, as well as their family members (asked of Cohort 2 only), the people they lived with, and their support workers. We were interested in cases that had been confirmed by a doctor or a test, as well as cases where the person thinks they had COVID-19 but this was not confirmed by a doctor or test. The data for these questions are reported in Figures 2.7-2.9.

<sup>5</sup> <https://www.understandingsociety.ac.uk/topic/covid-19> (accessed 19 March 2021)

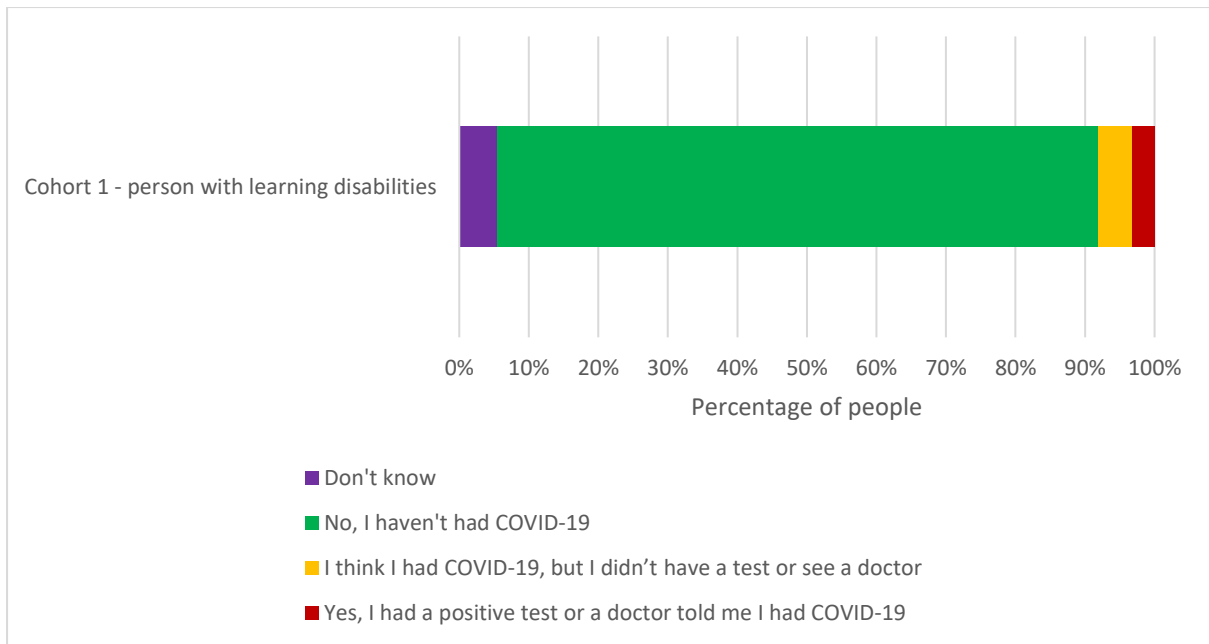


Figure 2.7. Do you think you have had COVID-19? (Cohort 1 only)

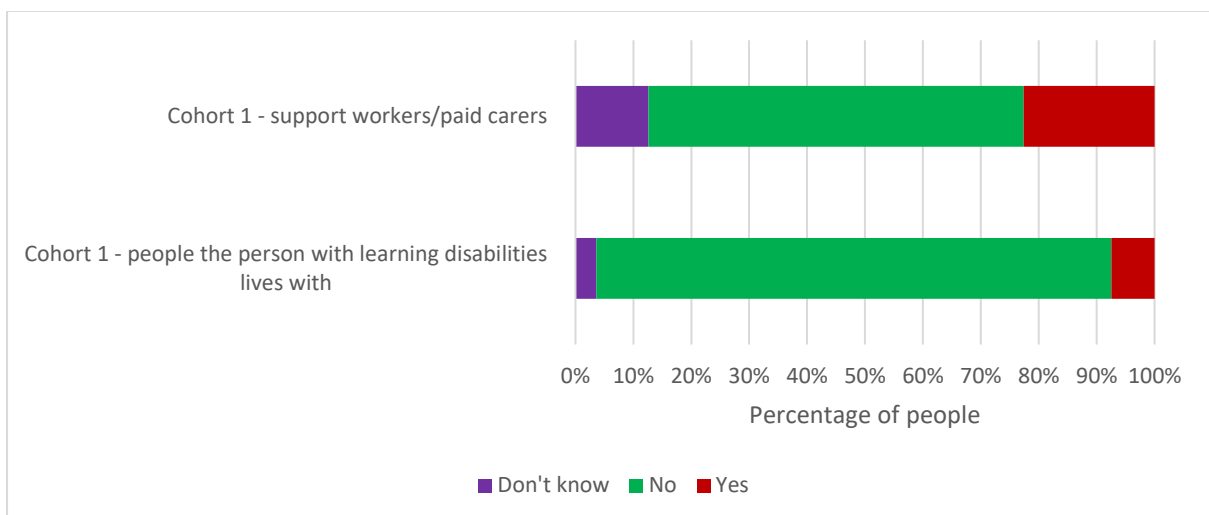


Figure 2.8. Who has had COVID-19 (Cohort 1 only)

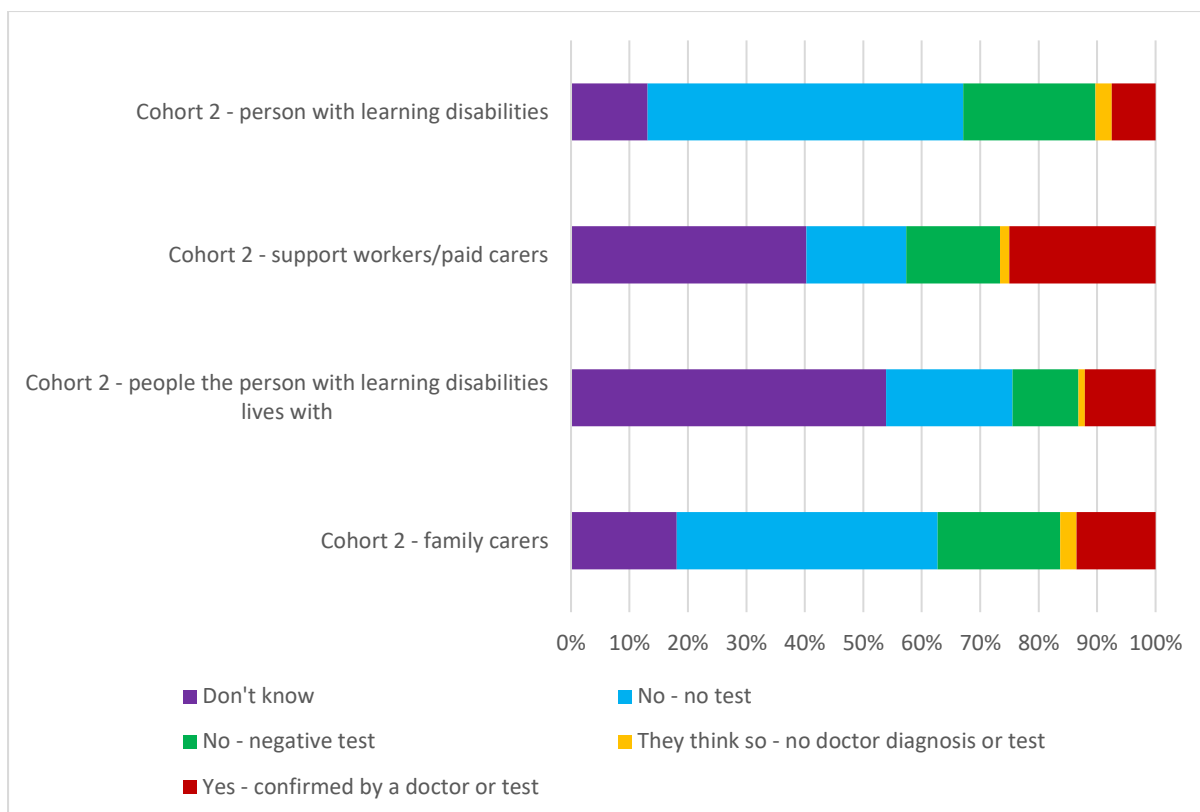


Figure 2.9. Who has had COVID-19 (Cohort 2 only)

Around one in ten people with learning disabilities within our sample thought (or their carers thought, in the case of Cohort 2) that they had had COVID-19 (Cohort 1 = 8%, Cohort 2 = 12%). In Cohort 2, family carers/paid support staff of people with learning disabilities who lived with their family were 3.5 times less likely ( $p < .001$ ) to report they thought that the person they support/care for had had COVID-19 than people with learning disabilities who lived elsewhere.

The group who appeared to be most likely to have had, or were thought to have had, COVID-19 were paid support staff (Cohort 1 = 23%, Cohort 2 = 27%).

Of those 50 people with learning disabilities in Cohort 1 who had had, or thought that they had had, COVID-19, eight (16%) had been hospitalised because of their COVID-19 symptoms. In Cohort 2, of the 43 people with learning disabilities who had a confirmed or suspected case of COVID-19, six (14%) were hospitalised because of their COVID-19 symptoms. These data can be compared to those in the Understanding Society COVID-19 Survey<sup>6</sup>: of the 391 people surveyed in November 2020, none of the respondents reported having had an inpatient hospital stay.

<sup>6</sup> <https://www.understandingsociety.ac.uk/topic/covid-19> (accessed 19 March 2021)

For the eight participants in Cohort 1 who had been hospitalised because of their COVID-19 symptoms, we asked them an additional question about what it was like being in the hospital being treated for COVID-19 (Box 2.1).

“It wasn't very nice, the NHS was very stretched, they were rushing around and very strict with all the patients. They wouldn't let my mum come to the hospital.”

“It was alright, it felt different to being in hospital before.”

“I did not like it as I was on my own every time. The staff were brilliant, but I couldn't wait to go back home.”

“It was quite strange as you are in a room on your own isolated always.”

“I was terrified.”

“Nerve-wracking. I caught the virus whilst in the hospital with an infection. It wasn't the same because I wasn't allowed any visitors. I felt isolated. I was discharged after around a week and then had to go back in because of the coronavirus for a few days.”

Box 2.1. What was it like being in the hospital because of COVID-19 symptoms? (Cohort 1 only)

Of the eight people with learning disabilities in Cohort 1 who had been hospitalised because of COVID-19, almost all reported that their experience of being in hospital with COVID-19 was scary and isolating as they were in a room on their own and were not allowed to have any visitors. People said that this experience was very different to being in hospital before.

### **2.2.3. Shielding, NHS Test and Trace app, and self-isolating**

We asked participants in both cohorts about shielding, separating this into whether people with learning disabilities had ever shielded, and whether they were currently shielding. We added more options in the Cohort 2 survey to include whether the person with learning disabilities received a shielding letter, or whether their “shielding” was self-imposed. These options were not provided to Cohort 1. These data are presented in Table 2.4.



Table 2.4. Shielding at all since March 2020, including current shielding

	Cohort 1	Cohort 2
<b>They have shielded since March 2020</b>		
Yes – shielding letter without being requested		23%
Yes – shielding letter after being requested		5%
Yes – self-imposed “shielding”		30%
Yes	31%	
No	69%	41%
Don't know		2%

Of the 193 people with learning disabilities in Cohort 1 and 216 people with learning disabilities in Cohort 2 who had shielded at any point since March 2020, 62% in Cohort 1 and 74% in Cohort 2 were shielding at the time of their interview or survey completion.

Participants in Cohort 1 were asked whether they had downloaded the NHS Test and Trace (or other country-specific) COVID-19 app to their mobile telephone, and whether or not they used it. These data are presented in Figure 2.10.

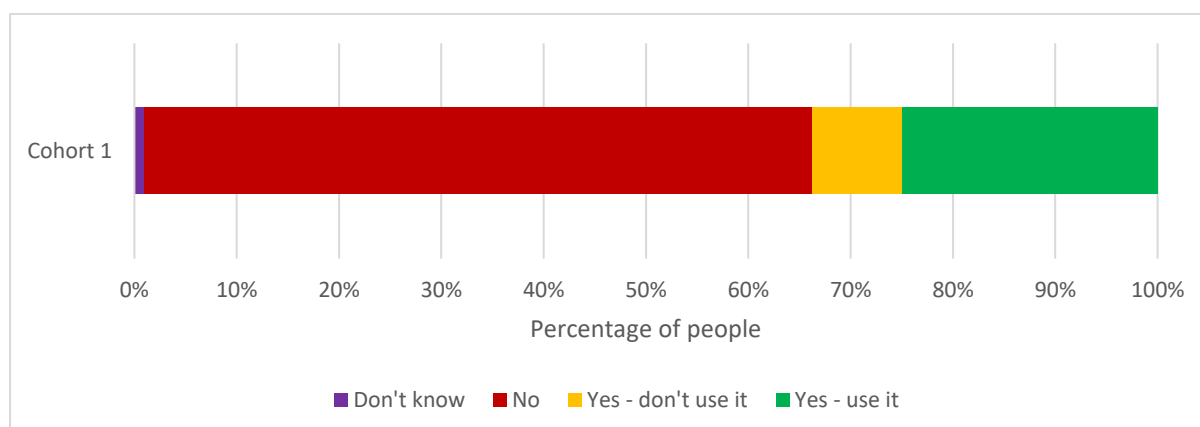


Figure 2.10. Have you downloaded the NHS COVID-19 app, the Stop COVID NI app, or the Protect Scotland app onto your mobile phone to use? (Cohort 1 only)

Of all the people with learning disabilities in Cohort 1, 25% had downloaded the NHS COVID-19 app (or country-specific equivalent) and were using it, and a further 9% had downloaded it but were not using it. To put this figure into context, 602 people with learning disabilities in Cohort 1 (98% of the sample) had a telephone from which they could make calls; although we do not know how many of those were mobile telephones that were internet enabled with the capability to have the NHS COVID-19 app downloaded onto them. There are more data about digital inclusion (i.e., access to the internet, having a mobile telephone) in [section 2.4.5](#).

In Cohort 1, people with learning disabilities who were aged 45 and over were 2.89 times less likely to have downloaded the NHS COVID-19 app (or country-specific equivalent) compared to people with learning disabilities aged 44 and under ( $p < .001$ ).

We also asked participants in both cohorts about self-isolation in the last four weeks because of COVID-19 symptoms or being in close contact with someone who had COVID-19. The percentages of people with learning disabilities who self-isolated in the last four weeks in both cohorts are displayed in Figure 2.11.

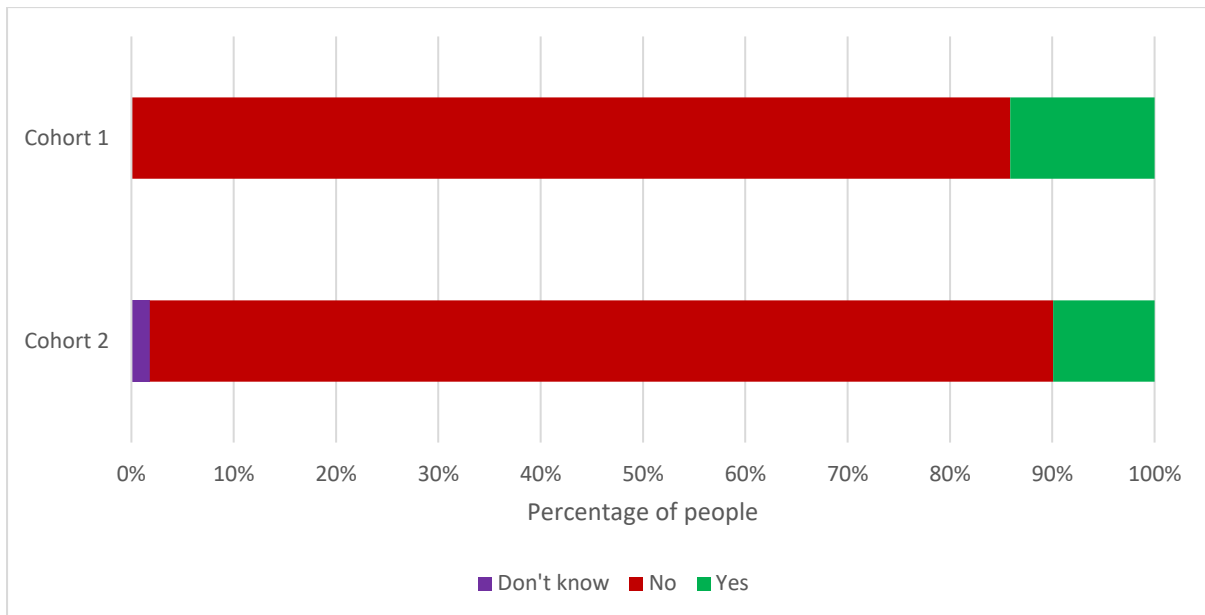


Figure 2.11. Person with learning disabilities self-isolated in the last four weeks because of COVID-19 symptoms or close contact with someone who had COVID-19 symptoms

The vast majority of people with learning disabilities in both cohorts (Cohort 1 = 86%, Cohort 2 = 88%) had not self-isolated. In Cohort 2, people who lived with their family were 2.1 times less likely ( $p = .01$ ) to have recently self-isolated, compared to people with learning disabilities who lived elsewhere.

#### 2.2.4. Personal protective equipment (PPE) and face masks/coverings

We asked people in both cohorts whether family carers/paid support staff wore PPE. We then asked follow-up questions for participants in Cohort 2 about whether they had had any difficulties in accessing PPE, and whether them wearing PPE had had an impact on the relationship between the family carer/paid support staff participant and the person with learning disabilities. These data are presented in Table 2.5.

Table 2.5. Family carer/paid support staff use of PPE

	Cohort 1	Cohort 2
<b>Family carers/paid support staff wear PPE</b>		
Yes	64%	48%
No	36%	51%
Don't know		1%
<b>Difficulties in family carer/paid support staff accessing PPE (n = 179)</b>		
Yes – difficulties in the past, okay now		25%
Yes – still have difficulties		7%
No		62%
Don't know		5%
<b>Impact of carer PPE on relationship of the family carer/paid support staff and person with learning disabilities (n = 179)</b>		
Negative impact		27%
Not much difference		72%
Positive impact		1%

Of the 179 family carers and paid support staff in Cohort 2 who wore PPE when caring for people with learning disabilities, 32% of them found it difficult (either in the past or at present) to access PPE. Family carers/paid support staff of people with learning disabilities aged 45 and over were 1.8 times ( $p = .02$ ) and 2.6 times ( $p = .01$ ) more likely to have worn PPE than family carers/paid support staff of people aged 44 and under.

In Cohort 2, family carers/paid support staff of people with learning disabilities were 2.7 times more likely to have difficulties accessing PPE when the person they cared for lived with their family, compared to people with learning disabilities living elsewhere ( $p < .001$ ).

Overall, 27% of family carers and paid support staff in Cohort 2 reported that wearing PPE had a negative impact on their relationship with the person they support/care for. In Cohort 2, family carers/paid support staff of people with learning disabilities who lived with their families were 2.7 times less likely to report that wearing PPE had negatively affected the relationship with the person they support/care for, compared to people with learning disabilities who lived elsewhere ( $p = .01$ ).

We asked people with learning disabilities in Cohort 1 how they felt about their family carers/paid support staff wearing PPE, and these data are presented in Box 2.2.

"I feel protected. It keeps everyone safe."

"It's better so that I'm not on my own."

"Scared. Sometimes carers have to take mask down to be understood."

"I like it, but at the beginning I wasn't sure. It frightened me at the beginning."

"Sometimes they do and sometimes they don't, but I know they should."

"Fine. One support worker I had to tell her to wear it."

"I feel okay about it, but masks upset me because I know there is something not quite right and it makes me sad."

"It feels a bit strange, like I'm in the twilight zone."

"It's OK but it's harder to hear what people are saying because I wear a hearing aid."

"Makes me feel like they are medical professionals - before they felt more normal, more as friends. Almost makes it less accessible."

"I changed provider and that makes it harder to make new relationships as I have not seen their face."

"Mixed feelings - I understand why they had to do it - but didn't like it outside as I don't like to be recognised as vulnerable person."

"My family doesn't wear it because I don't want them to. I find it a bit stupid that the carers have to wear it. I feel sorry for them because it is not nice to wear them. Wearing clean clothes should be enough."

Box 2.2. How do you feel about your family or carers wearing PPE (for example, masks, gloves, aprons) (if they didn't normally)? (Cohort 1 only)

People with learning disabilities in Cohort 1 were generally happy or accepting about their family or carers wearing PPE, acknowledging that it was necessary to keep everyone safe. Some difficulties were reported by people with learning disabilities, including having difficulties in understanding what their family or carers were saying and face masks/coverings making it more difficult to build relationships with new support workers as they had never seen their faces. For the people who felt nervous or scared by their family or carers wearing PPE, some of the specific reasons given were that it made them look like doctors and that it reminded them that something was wrong.

We also asked whether people with learning disabilities were wearing face masks/coverings when they were going out, and what their experiences of wearing these were. These data are presented in Table 2.6.

Table 2.6. Use of face masks/coverings by people with learning disabilities

	Cohort 1	Cohort 2
<b>Worn a face mask/covering in last 4 weeks</b>		
Yes	86%	56%
No	10%	27%
Don't know	0%	3%
Not been out in last 4 weeks	3%	14%
<b>Exempt from wearing face mask/covering</b>		
Yes	20%	52%
No	79%	16%
Don't know	1%	32%
<b>Reasons for not wearing face mask/covering</b>		
Does not understand why they have to wear one		36%
They make it difficult to breathe	61%	9%
They find it uncomfortable to wear	26%	14%
They might have a seizure	7%	7%
They get a skin irritation from them	3%	3%
They make it hard for them to communicate	0%	10%
Other	0%	10%

Fewer people with learning disabilities in Cohort 2 (56%) had been wearing face masks/coverings than people in Cohort 1 (86%), even accounting for the larger proportion of people with learning disabilities in Cohort 2 who had not been out in the last four weeks. This may be explained by findings that a much larger percentage of people with learning disabilities in Cohort 2 were exempt from wearing a face mask/covering (53%), compared to Cohort 1 (20%). In Cohort 2, family carers/paid support staff of people with learning disabilities aged 45 and over were 3.7 times less likely to report that the person they support/care for was exempt from wearing a face mask/covering, compared to those aged 44 and under ( $p < .001$ ).

Of the 62 people in Cohort 1 who did not wear a face mask/covering when they went out, 22 (36%) reported that they were made to feel bad about it by other people.

## 2.2.5. Deaths from COVID-19

One of the particularly pressing COVID-19-specific questions for people with learning disabilities identified by our advisory groups was how many people knew someone who had died from COVID-19. These data are displayed in Figures 2.12 and 2.13.

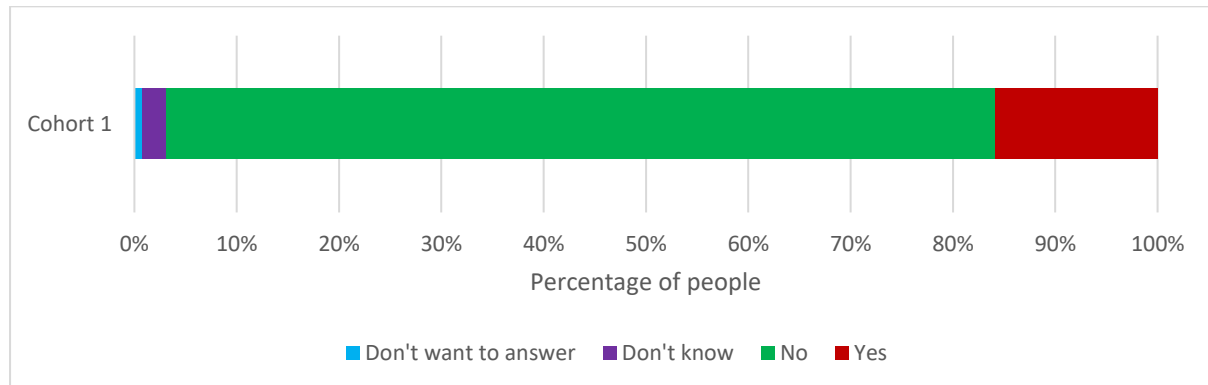


Figure 2.12. Have any friends or family members died from COVID-19? (Cohort 1 only)

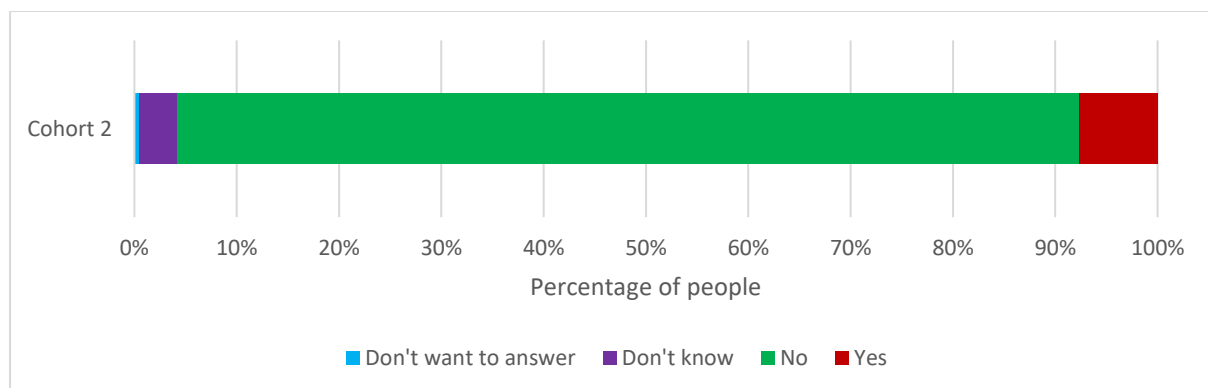


Figure 2.13. Has anyone close to the person you support/care for died from COVID-19? This could be a family member and friend, a person they were sharing a house with or a person who supported them. (Cohort 2 only)

From these two figures (2.12 and 2.13), we can see that number of people with learning disabilities in both Cohort 1 and Cohort 2 (N = 98 and 29 respectively) have experienced someone close to them die due to COVID-19, with this proportion being largest for Cohort 1 (16% vs 8% in Cohort 2). As can be seen in the figure titles, the questions for both cohorts were worded slightly differently, and this might have had an impact on the responses. Our results can be compared to a general population sample from the Impact of COVID-19 on Wellbeing in Scotland Survey<sup>7</sup>, where 9% of their sample of 1000 people surveyed had lost a friend or family member to COVID-19.

<sup>7</sup> <https://www.gov.scot/publications/impact-covid-19-wellbeing-scotland/> (accessed 19 March 2021)

## 2.2.6. COVID-19 vaccinations

Another pressing question for people with learning disabilities in our advisory groups at the time of deciding questions for Wave 1 was how many people with learning disabilities would take a COVID-19 vaccine if they were offered it. These data are displayed in Figure 2.14.

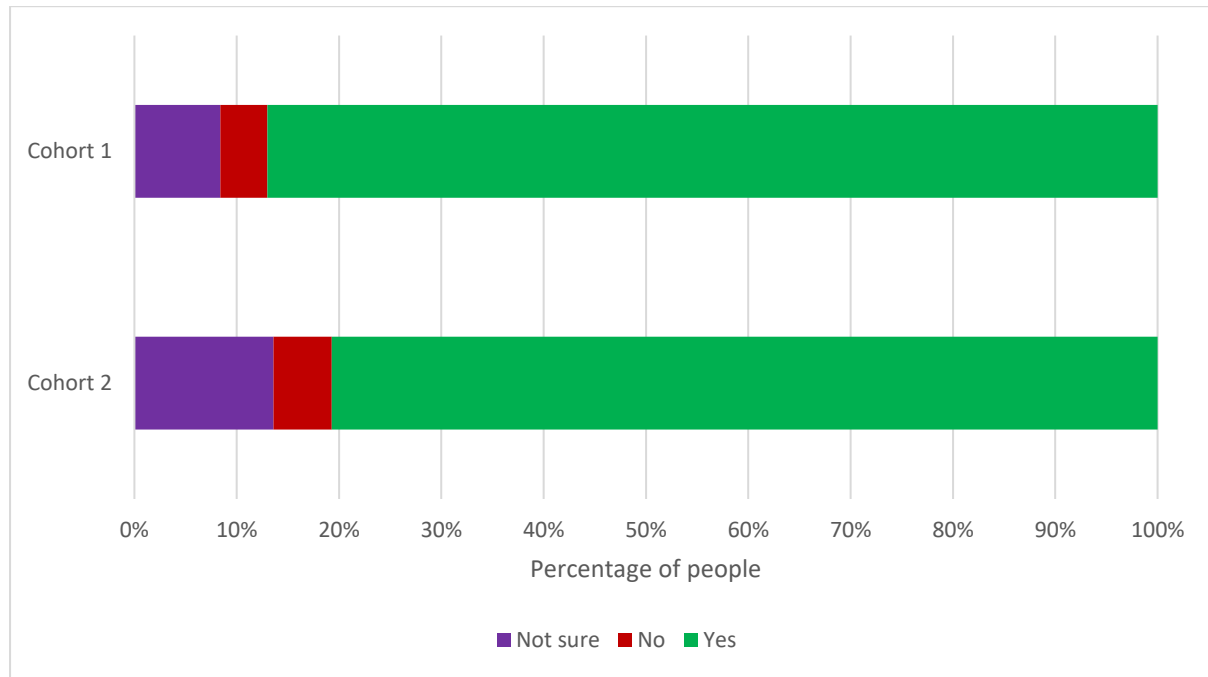


Figure 2.14. COVID-19 vaccine acceptance if offered to people with learning disabilities

The vast majority of participants in both cohorts (>80%) indicated that they, or the person they supported/cared for, would take the COVID-19 vaccine if it were offered to them. These data are broadly comparable to those in the Understanding Society COVID-19 Survey<sup>8</sup> in November 2020: 76% of the 391 respondents in the general population stated that they would be likely or very likely to take up a COVID-19 vaccine.

We asked participants in Cohort 2 about the support that would be needed for the person they support/care for to be able to have their COVID-19 vaccination. These data are presented in Box 2.3.

<sup>8</sup> <https://www.understandingsociety.ac.uk/topic/covid-19> (accessed 19 March 2021)

“He would need intensive support as afraid of needles and cannot understand the purpose of being vaccinated.”

“I would need to accompany her, she could not do this alone, especially not since she does not talk.”

“Support to stay still and to cooperate while the vaccine is being given.”

“They would need a visual story to prepare them and the environment they would visit to receive the vaccine. They would need motivator to engage them with while they would be administered with the vaccine. Support workers would need to be in attendance also.”

“He would have to have some form of restraint to keep him still. This is the case for all inoculations & health and personal care interventions.”

“She would probably need to be distracted or given a sedative to make sure she was calm.”

“It would need to be in a familiar place (e.g., Doctors surgery).”

“Lots of encouragement and going with a supportive, calm person who is known well.”

Box 2.3. Would there be any particular support needed for the person you support/care for to be able to have their COVID-19 vaccinations? (Cohort 2 only)

Participants in Cohort 2 outlined several ways the people they support/care for would need to be supported to receive their COVID-19 vaccine. The most common were to be accompanied by one or more people who they trust and know well, and to have the information about the vaccination explained in a way that they understand (e.g., Easy Read, social stories, language that they understand). Other common responses included having the vaccine in a familiar place, and to have some form of restraint or sedation to enable the vaccination to go ahead. The level of restraint or sedation suggested by some participants in Cohort 2 varied from having someone to hold their arm still (as their natural reaction was to pull it away if someone approaches them), through to being under general anaesthetic so that the vaccine could be given.



## **2.3. Physical health and access to health services**

In this sub-section we report the findings from questions in the interviews and surveys about the physical health of people with learning disabilities and their access to health services during the COVID-19 pandemic, including:

- the current health of people with learning disabilities,
- what has happened to existing health services that people with learning disabilities used regularly before March 2020,
- what has happened to planned medical tests, appointments and operations, and
- what is happening with preventative health measures for people with learning disabilities (e.g., annual health check, flu vaccination).

### **2.3.1. Current health of people with learning disabilities**

We asked participants about their health (Cohort 1) or the health of the person with learning disabilities who they support/care for (Cohort 2). All data for these questions are displayed in Table 2.7.

Table 2.7. The current health status of people with learning disabilities

	<b>Cohort 1</b>	<b>Cohort 2</b>
<b>Health today</b>		
Good	60%	52%
OK	33%	36%
Not very good	6%	
Not good		11%
Don't know	1%	1%
<b>Has physical health changed since the first lockdown in March 2020</b>		
Worse		30%
About the Same		63%
Better		7%

When asked about their general health today, people with learning disabilities in Cohort 1 most commonly rated their health as good (60%), and this was similar for Cohort 2, where 52% of participants reported health as good for the person with learning disabilities they supported/cared for. In Cohort 1, people with learning disabilities aged 45 and over were 1.5 times less likely to rate their health as good, compared with participants aged 44 and under ( $p = .04$ ). People with learning disabilities in Cohort 1 who were living with their family were 1.8 times more likely to rate their health as good, compared to people living elsewhere ( $p = .01$ ).

In Cohort 2, most family carers/paid support staff said that the health of the person they care for/support had stayed about the same since the start of the first national lockdown in March 2020, although almost a third (30%) said the person's health had changed for the worse.

Participants in Cohort 2 were asked about whether the person they support had been admitted to hospital for a reason unrelated to COVID-19; these data are reported in Table 2.8.

Table 2.8. Since the start of the first lockdown in March 2020, has the person you support/care for had a hospital admission for a reason not related to COVID-19? (Cohort 2 only)

<b>Cohort 2</b>	
<b>Hospital admission not related to COVID-19</b>	
Yes	13%
No	86%
Don't know	1%

Of the 46 people with learning disabilities reported about in Cohort 2 who had been admitted to hospital for a reason unrelated to COVID-19, 82% were allowed to have a carer stay with them during their admission.

We also asked participants in Cohort 2 whether they had experienced difficulties in getting essential equipment and resources, and these data are presented in Figure 2.15.

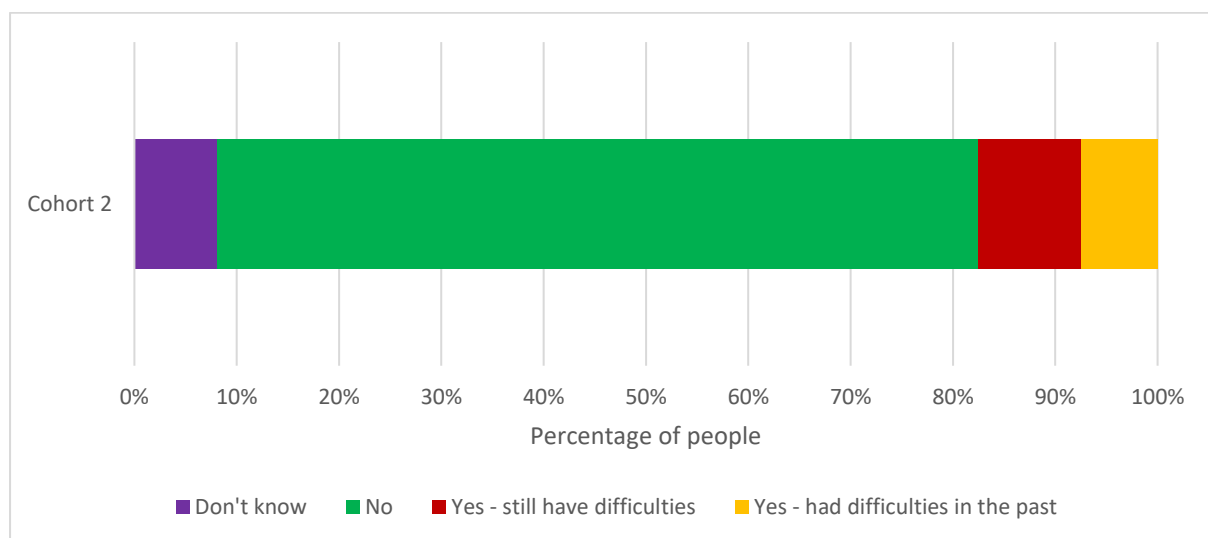


Figure 2.15. Have there been difficulties getting and keeping essential equipment and resources for the person you support/care for? (Cohort 2 only)

Of the 61 family carers/paid support staff in Cohort 2 who reported that they had had difficulties in getting and keeping essential equipment for the person they care for, 57% were still having difficulties at the time of reporting. In Cohort 2, family carers/paid support staff of people with learning disabilities aged 45 and over were 4.7 times less likely to report that they had experienced difficulties in getting and keeping essential equipment for the person they care for, compared to those who support/care for people with learning disabilities aged 44 and under ( $p < .001$ ).

### 2.3.2. Existing health services for people with learning disabilities

Generally, people with learning disabilities who saw their healthcare professionals regularly before the first lockdown in March 2020 reported seeing them less since the first lockdown. Of all the people with learning disabilities included in both cohorts, Table 2.9 reports how many were regularly seeing different healthcare professionals before March 2020.

Table 2.9. People with learning disabilities who saw each healthcare professional regularly before the March 2020 lockdown

	<b>Cohort 1</b>	<b>Cohort 2</b>
<b>GP</b>	43%	46%
<b>Community nurse</b>	22%	32%
<b>Psychiatrist/clinical psychologist/counsellor</b>	21%	27%
<b>Other therapist</b>	15%	37%

The following figures (Figures 2.16-2.19) present data about whether the percentage of people with learning disabilities who saw each healthcare professional regularly before the March 2020 lockdown had seen them since the start of that first lockdown.

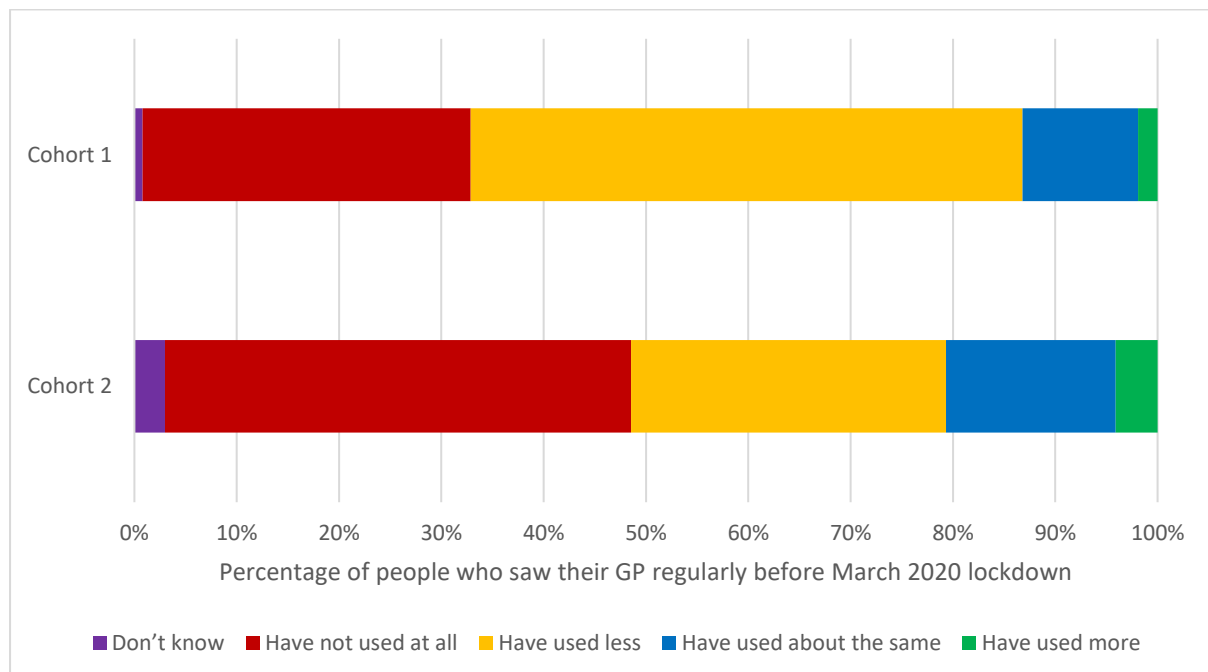


Figure 2.16. The percentage of people with learning disabilities who have seen their GP as much as before the March 2020 lockdown (Sample: Cohort 1 (n=265), Cohort 2 (n=172))

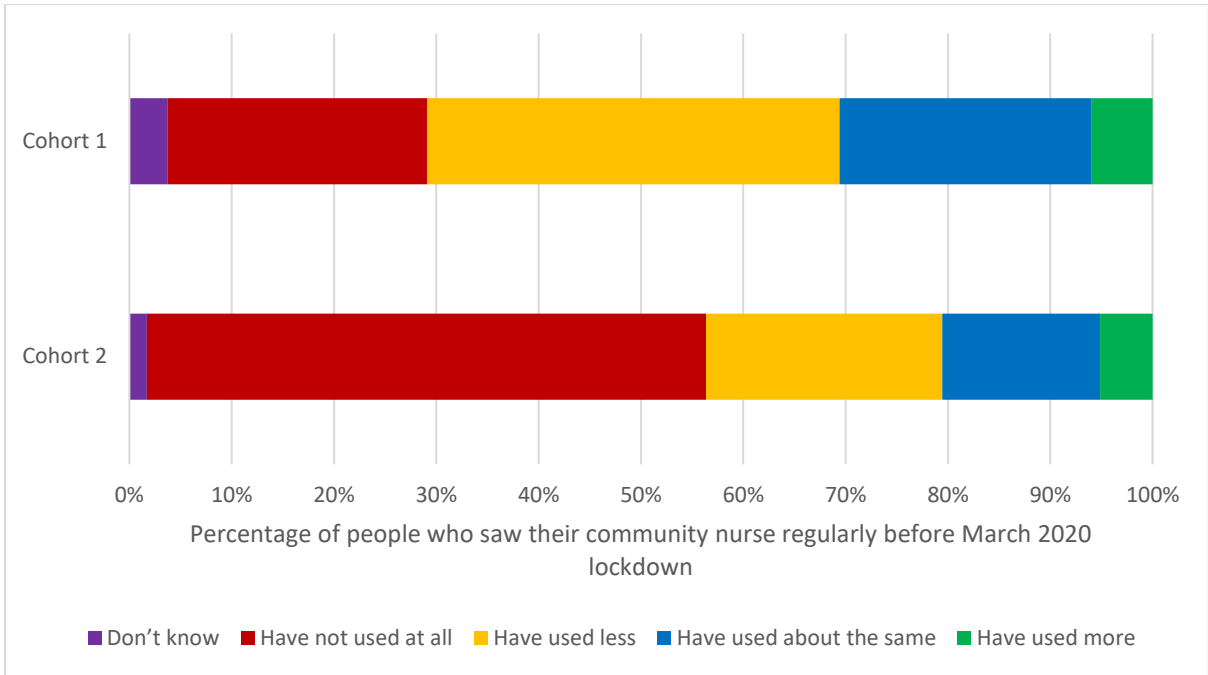


Figure 2.17. The percentage of people with learning disabilities who have seen their community nurse as much as before the March 2020 lockdown (Sample: Cohort 1 (n=134), Cohort 2 (n=118))

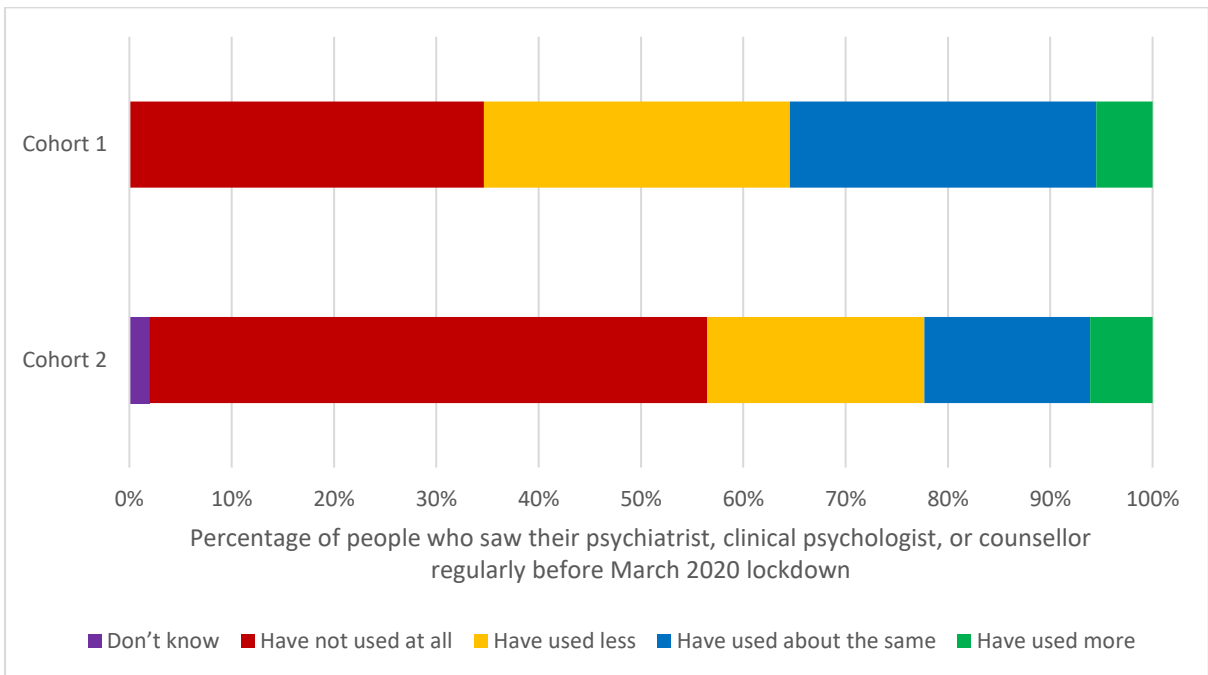


Figure 2.18. The percentage of people with learning disabilities who have seen their psychiatrist, clinical psychologist or counsellor as much as before the March 2020 lockdown (Sample: Cohort 1 (n=127), Cohort 2 (n=99))

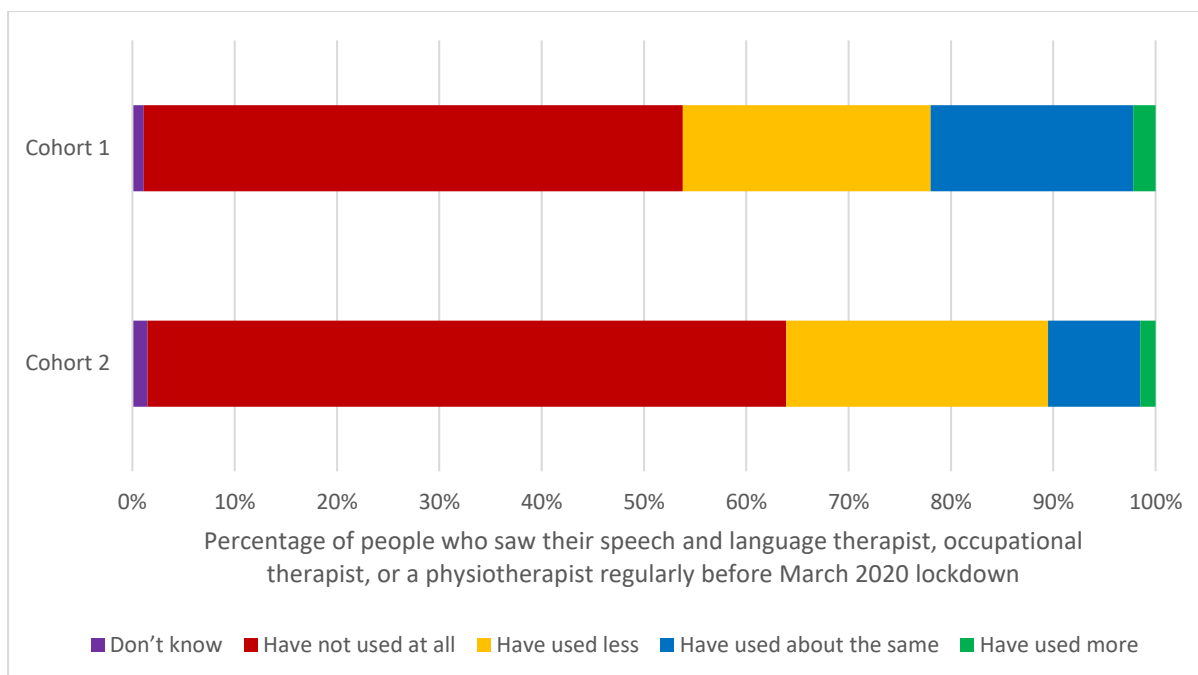


Figure 2.19. The percentage of people with learning disabilities who have seen their speech and language therapist, occupational therapist, or physiotherapist as much as before the March 2020 lockdown (Sample: Cohort 1 (n= 91), Cohort 2 (n= 144))

In all four instances, and across both cohorts, over 60% of people with learning disabilities who had routinely seen these healthcare professionals before the first lockdown in March 2020 had seen them less or not at all since then.

The most frequent response was that they hadn't seen healthcare practitioners at all, which was the case for 32% of people with learning disabilities in Cohort 1 and 46% in Cohort 2 who used to regularly see a GP, 25% in Cohort 1 and 54% in Cohort 2 with respect to community nurses, 35% in Cohort 1 and 55% in Cohort 2 regarding Psychiatrists, Clinical Psychologists and Counsellors and 53% in Cohort 1 62% in Cohort 2 with regards to seeing other types of therapists. In Cohort 2, family carers/paid support staff of people with learning disabilities aged 45 and over were 9.1 times less likely to report that the person they support/care for had experienced reduced contact with their speech and language therapist, occupational therapist, or physiotherapist, compared to those aged 44 and under ( $p < .001$ ).

### 2.3.3. Planned medical tests, appointments, and operations

We also asked about what had happened to planned medical tests, outpatient hospital appointments, and operations since the first lockdown in March 2020. These data are presented in Table 2.10 for both cohorts.

Table 2.10. People with learning disabilities who had planned medical tests, operations or appointments cancelled since the March 2020 lockdown

	Cohort 1	Cohort 2
<b>Planned medical test cancelled</b>		
Yes	22%	28%
No	65%	65%
Don't know	13%	7%
<b>Planned medical operation cancelled</b>		
Yes	4%	5%
No	79%	92%
Don't know	17%	3%
<b>Planned hospital appointment cancelled</b>		
Yes	23%	41%
No	65%	52%
Don't know	12%	7%

Over one-fifth of people with learning disabilities in both cohorts had had a medical test or a hospital appointment cancelled since the first lockdown, with as many as 41% of people with learning disabilities in Cohort 2 having had a planned hospital appointment cancelled; a higher percentage than for people with learning disabilities in Cohort 1 (23%). In Cohort 2, family carers/paid support staff of people with learning disabilities aged 45 and over were 1.9 times less likely to report that the person they support/care for had experienced a cancellation to a planned hospital appointment, compared to those aged 44 and under ( $p = .04$ ).

#### 2.1.4. Preventative health measures

Adults with learning disabilities are eligible to have an annual health check with their GP to check and talk about their general health and to spot the early signs of health conditions (e.g., diabetes). They can help people with learning disabilities to get to know their GP better, which can help them to feel more comfortable contacting them if they do get ill. Further information about annual health checks is presented in Figure 2.20 for Cohort 1 and Figure 2.21 for Cohort 2.

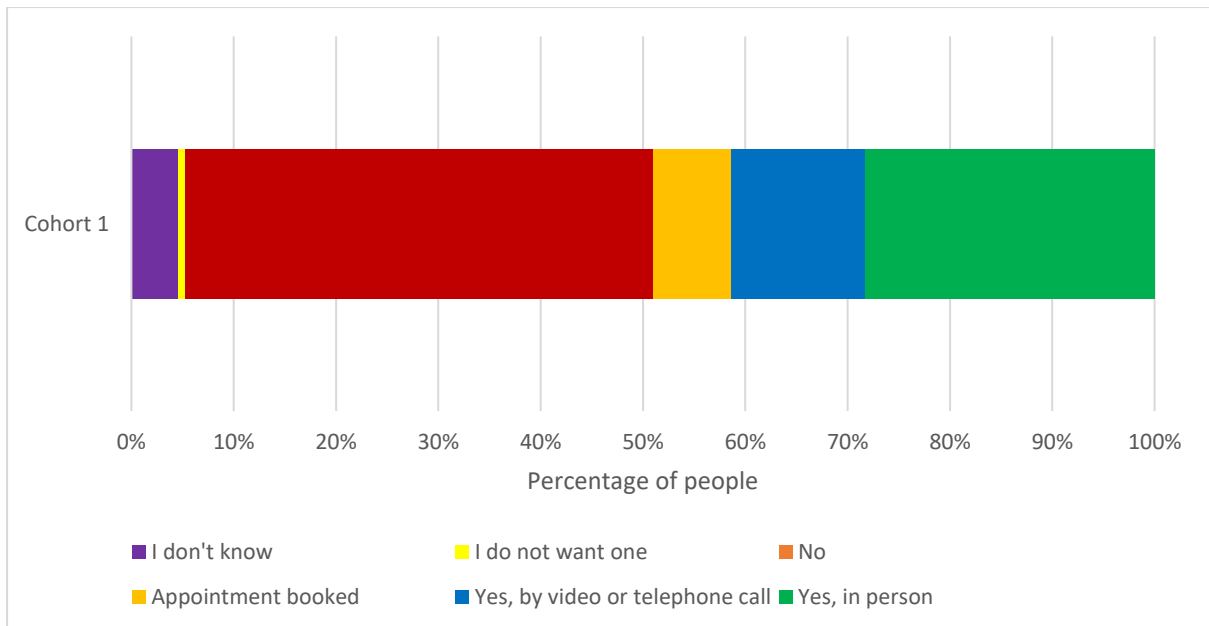


Figure 2.20. Since the start of the first COVID-19 lockdown in March 2020, have you had your annual health check? (Cohort 1 only, limited to only the 434 people who usually have an annual health check)

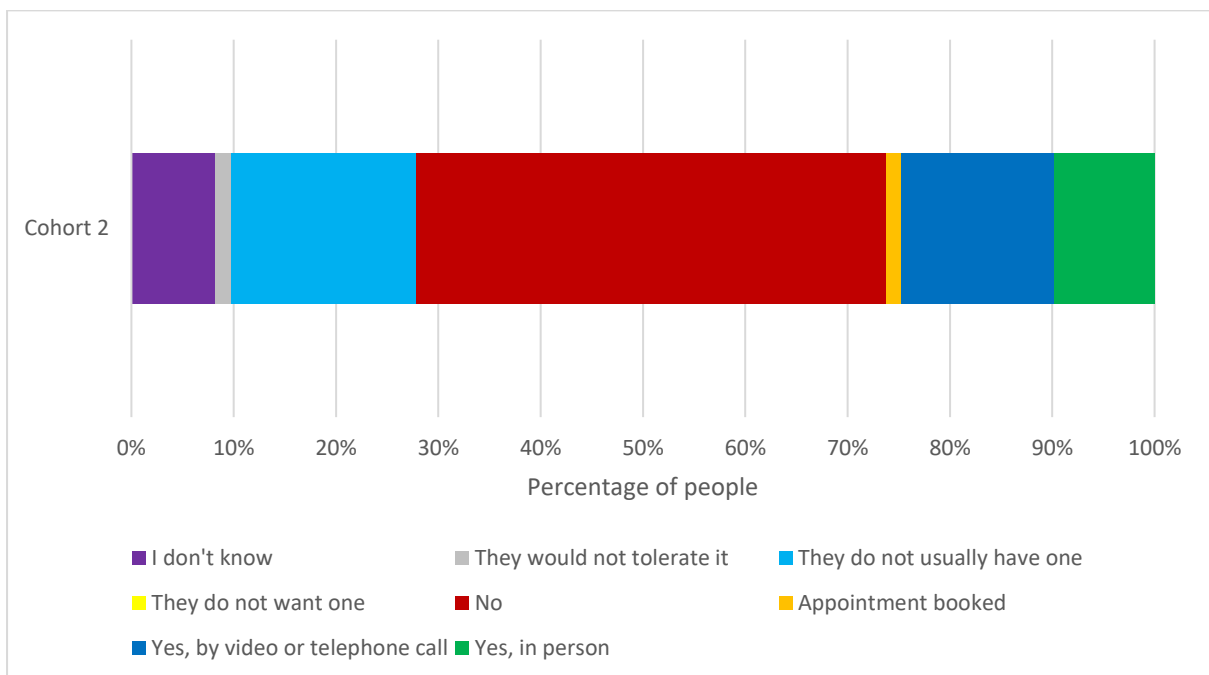


Figure 2.21. Since the start of the first lockdown in March 2020, has the person you support/care for had their annual health check? (Cohort 2 only)

Of the 434 people with learning disabilities in Cohort 1 who usually have an annual health check, 46% have not had one since the first national lockdown in March 2020. This is a similar picture to Cohort 2, where 46% of people with learning disabilities had not had their annual health check.

Adults with learning disabilities are eligible for a free flu vaccine. Information about the Winter 2020/21 flu vaccinations, for both Cohorts, are reported in Table 2.11.

Table 2.11. Flu vaccinations for people with learning disabilities

	<b>Cohort 1</b>	<b>Cohort 2</b>
<b>Flu vaccine</b>		
Yes	65%	70%
No	30%	17%
Don't want a flu vaccine	4%	3%
Would not tolerate a flu vaccination		6%
Don't know	1%	4%

In Cohort 1, 65% of people with learning disabilities reported having the flu vaccine in Winter 2020/21. In Cohort 2, 70% of people with learning disabilities were reported to have received the flu vaccine. In Cohort 2, family carers/paid support staff of people with learning disabilities aged 45 and over were 3.6 times more likely to report that the person they support/care for had received their Winter 2020/21 flu vaccine, compared to those aged 44 and under ( $p < .001$ ).



### 2.3. Wellbeing and mental health

In this section of the survey, we asked about the wellbeing of people with learning disabilities in the weeks before the interview (Cohort 1) or survey (Cohort 2). There were additional data collected about the wellbeing and mental health of people with learning disabilities in Wave 1, which we will report on in Wave 2 when we can report on changes over time.

We asked participants in Cohort 1 about their COVID-19-related worries, using an adapted version of the Pandemic Anxiety Scale<sup>9</sup>. Data related to all seven items in this scale are displayed in Figure 2.22.

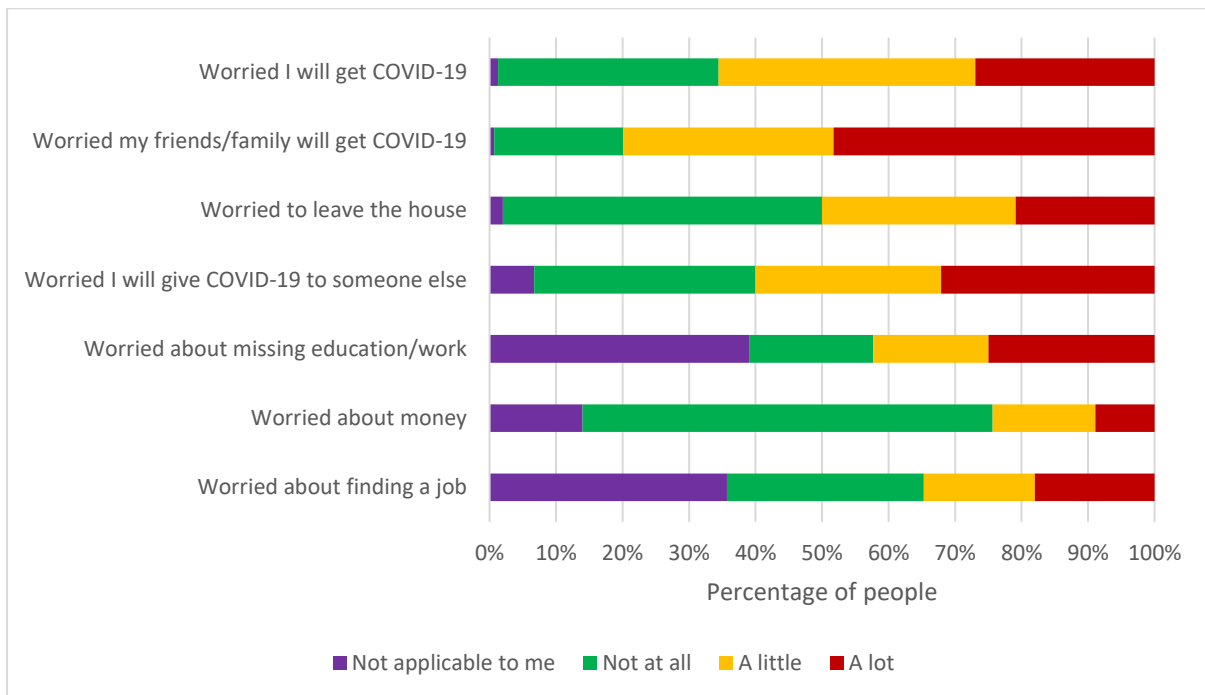


Figure 2.22. Questions on the Pandemic Anxiety Scale (Elroy et al., 2020) (Cohort 1 only)

People with learning disabilities were more concerned about their family or friends catching COVID-19, than they were about themselves catching it. As can be seen in Figure 2.22, 80% of participants showed at least a little concern that their friends/family will get COVID-19. Almost half (48%) were very concerned. Over half of the participants in Cohort 1 were at least a little worried to leave the house.

In Cohort 1, people with learning disabilities who were aged 45 and over were 1.6 times more likely to be (a little or a lot) concerned about leaving the house, compared to those aged 44 and under ( $p = .03$ ).

In Cohort 1, people with learning disabilities living with their family were 1.6 times more likely to be (a little or lot) worried about missing education or school than people living elsewhere ( $p = .04$ ).

<sup>9</sup> McElroy, E., Patalay, P., Moltrecht, B., Shevlin, M., Shum, A., Creswell, C., & Waite, P. (2020). Demographic and health factors associated with pandemic anxiety in the context of COVID-19. *British Journal of Health Psychology*, 25(4), 934-944.

We also asked some general questions about the wellbeing of people with learning disabilities in both cohorts, and these data are presented in Figures 2.23 and 2.24. For Cohort 1, we asked about their wellbeing in the past four week period, and for Cohort 2 we asked about how people with learning disabilities' wellbeing has changed since the start of the first lockdown in March 2020.

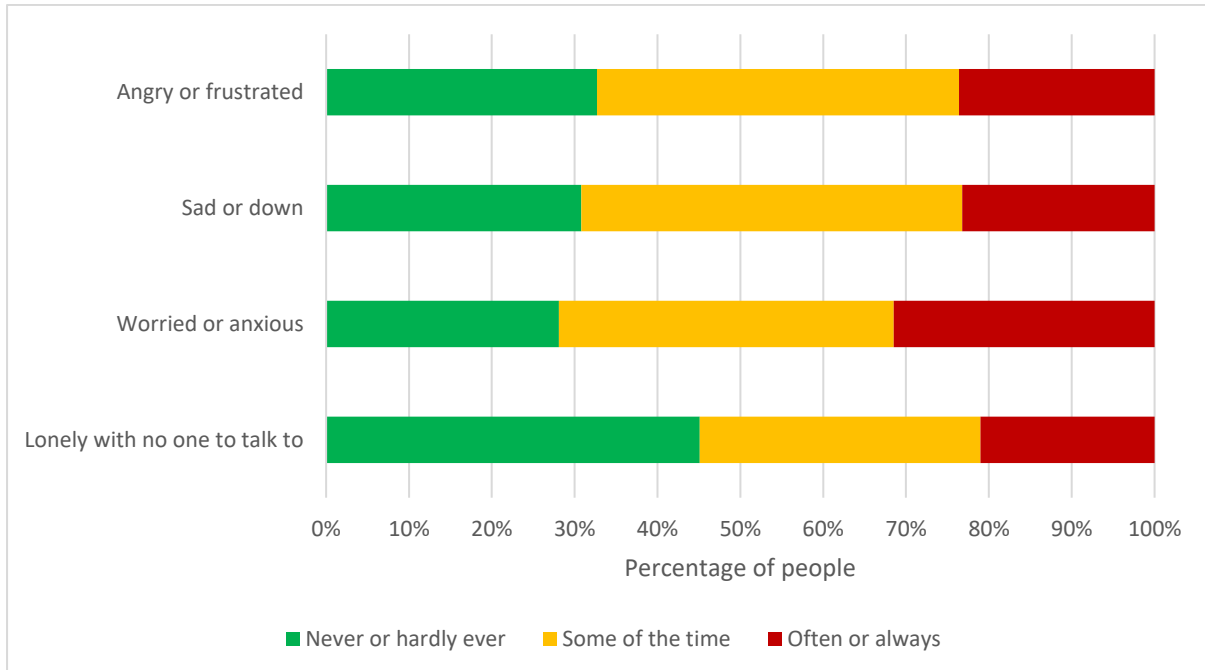


Figure 2.23. How people with learning disabilities have felt over the last four weeks (Cohort 1 only)

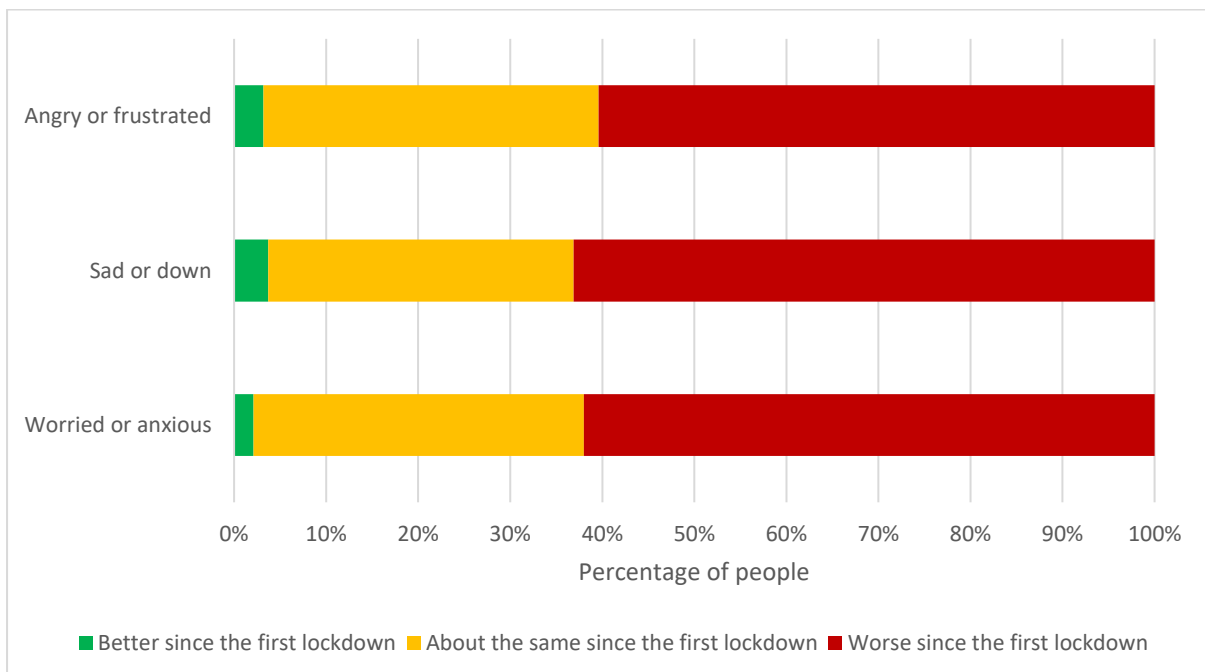


Figure 2.24. How people with learning disabilities have felt compared to before the start of the first lockdown in March 2020 (Cohort 2 only)

Most participants in Cohort 1 reported experiencing low levels of well-being over the last four weeks on all four questions, with over 65% of participants answering that they had felt angry or frustrated, sad or down, and worried or anxious at least some of the time over the last four weeks. In Cohort 1, people with learning disabilities living with their family were 1.5 times less likely to report feeling lonely ( $p = .02$ ) and 1.7 times less likely to feel sad or down (at least some of the time;  $p = .01$ ) than people living elsewhere.

Over 60% of participants in Cohort 2 reported that the person they support/care for had worse well-being since the start of the first lockdown in March 2020 on all three questions.

## **2.4. Relationships, social lives, and digital inclusion**

In this sub-section, we report the findings from questions about the relationships, social lives, and digital inclusion of people with learning disabilities during the COVID-19 pandemic. These are:

- how people with learning disabilities are staying in touch with their family and friends,
- about their relationship with their partner,
- how people with learning disabilities are getting on with the people they live with,
- about visitor restrictions where the people with learning disabilities live, and
- how people are using technology during the COVID-19 pandemic (digital inclusion).

### **2.4.1. Staying in touch with family and friends**

People with learning disabilities in Cohort 1 were asked about whether they were staying in touch with their friends and family as much as they wanted to, and these data are presented in Figure 2.25 below.

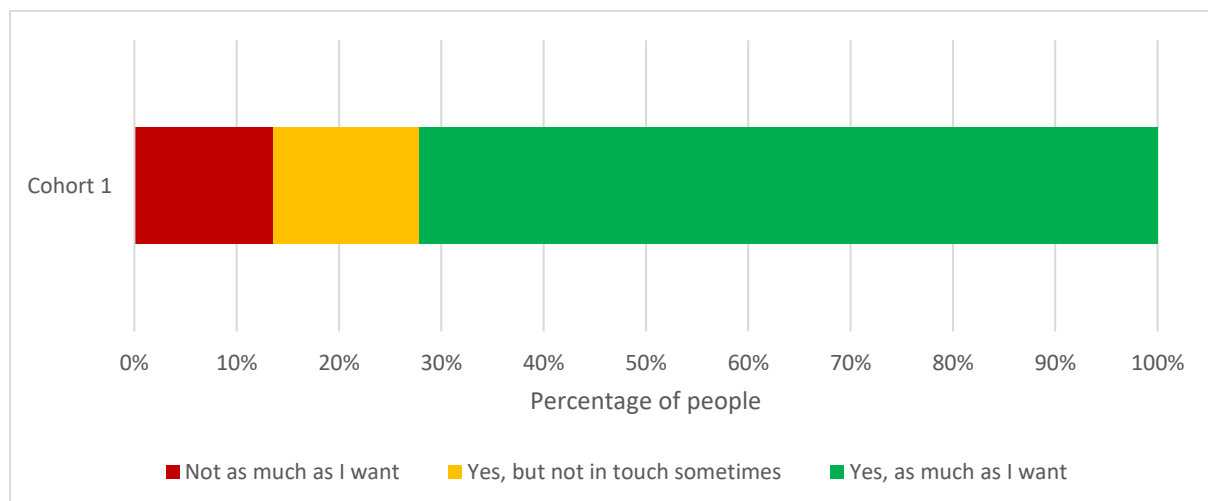


Figure 2.25. In the last four weeks have you been able to stay in touch with family and friends as much as you want? (Cohort 1 only)

Most people with learning disabilities in Cohort 1 reported that they were staying in touch as much as they wanted (72%), with 14% of people Cohort 1 reporting they were not staying in touch with the important people in their lives as much as they wanted.

We were also interested in understanding the ways in which people with learning disabilities in Cohort 2 had been staying in contact with others. The most common ways in which family carers and paid support staff in the Cohort 2 survey described people with learning disabilities staying in touch with other people are presented in Table 2.12.

Table 2.12. How people with learning disabilities stay in contact with friends, family and other people (Cohort 2 only)

		<b>Cohort 2</b>
<b>Face-to-face</b>		
	Do this now	11%
	Did prior to lockdown	32%
	Never did this nor do they now	5%
<b>Meet outside</b>		
	Do this now	9%
	Did prior to lockdown	34%
	Never did this nor do they now	6%
<b>Meet in others' house</b>		
	Do this now	3%
	Did prior to lockdown	32%
	Never did this nor do they now	10%
<b>Meet in own house</b>		
	Do this now	4%
	Did prior to lockdown	35%
	Never did this nor do they now	6%
<b>Meet in other indoor places</b>		
	Do this now	4%
	Did prior to lockdown	37%
	Never did this nor do they now	5%
<b>Talk on telephone</b>		
	Do this now	21%
	Did prior to lockdown	11%
	Never did this nor do they now	18%
<b>Through video calls</b>		
	Do this now	28%
	Did prior to lockdown	7%
	Never did this nor do they now	14%

Whilst face-to-face contact in and outdoors had inevitably decreased for the people with learning disabilities in Cohort 2, this appears to have been accompanied by an increase in contact via telephone (10% increase), and video calling (21% increase).

#### **2.4.2. Relationship with a partner**

From the total sample of 621 people in Cohort 1, 27% of people had a partner (e.g., husband, wife, boyfriend, girlfriend). Of these people, 26% lived with their partner. We asked all these participants about how well they had been getting on with their partner recently, and these data are displayed in Figure 2.26.

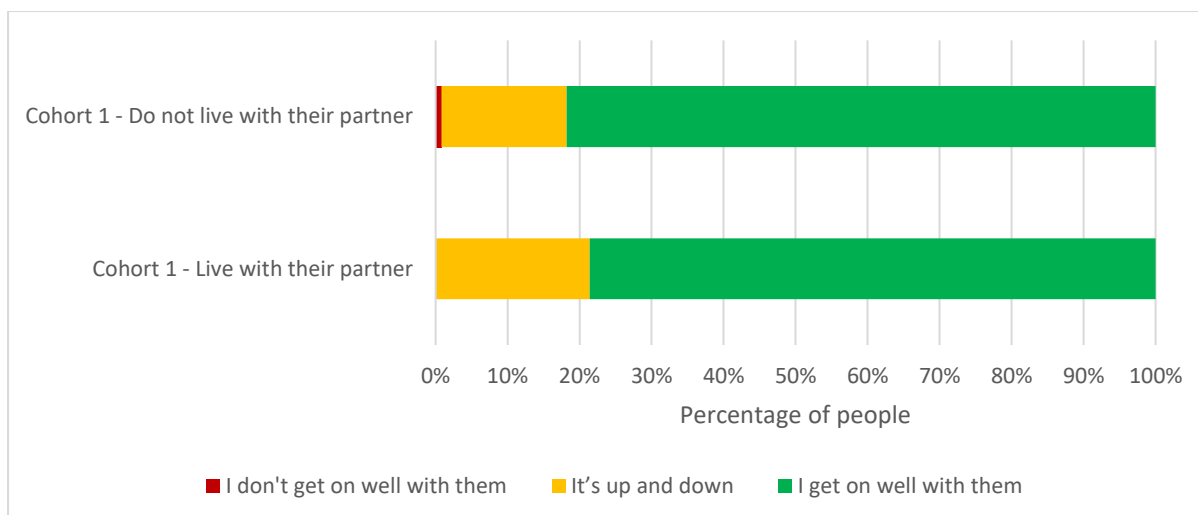


Figure 2.26. In the last four weeks, how have you been getting on with your partner? (Cohort 1 only; n = 165)

In Cohort 1, only 1% of people with learning disabilities who did not live with their partner reported that they were not getting on well with them. For everyone else, they were either getting on well or had ups and downs. The majority of participants (around 80%) were getting on well with their partner, whether they lived with them or not.

For people who had a partner who did not live with them, we asked about how they kept in contact with their partner. Information about how people with learning disabilities in Cohort 1 kept in contact with their partner is displayed in Table 2.13.

Table 2.13. How people with learning disabilities are keeping in contact with their partner over the last four weeks (Cohort 1 only)

<b>Cohort 1 (n = 165)</b>	
<b>Met their partner in person</b>	
Every day	29%
At least once a week	15%
Once or twice	18%
Never	38%
<b>Spoken to their partner on the telephone, on FaceTime, Zoom, Facebook, or text chat</b>	
Every day	53%
At least once a week	23%
Once or twice	6%
Never	18%

Whilst over one-third of people with learning disabilities (38%) reported that they had not seen their partner (when they did not live with them) over the last four weeks, the majority (82%) had had some virtual contact. In Cohort 1, people with learning disabilities aged 45 and over were 2.9 times less likely to have daily virtual contact with their partner than people with learning disabilities aged 44 and under ( $p = .01$ ).

### 2.4.3. Relationships with the people they live with

We also asked questions in both cohorts about how people with learning disabilities were getting on with the people they lived with. Figure 2.27 presents the data from these questions broken down by people who live with their family and people who live with other people with learning disabilities.

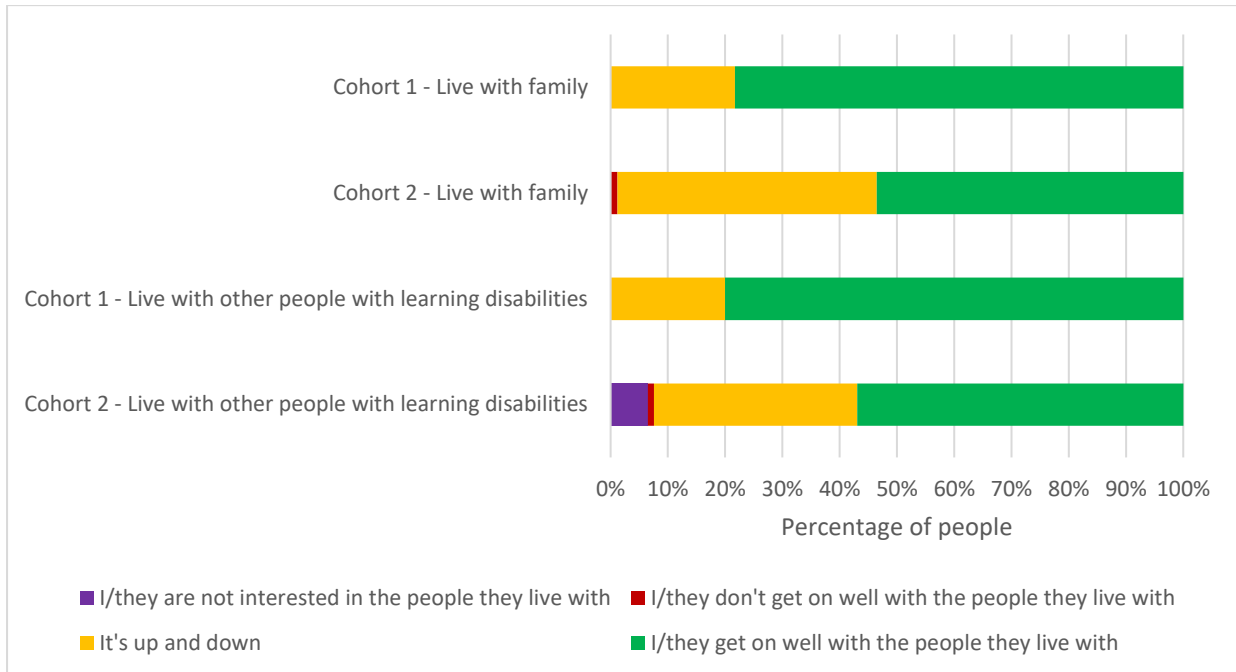


Figure 2.27. How people with learning disabilities have been getting on with the people they live with over the last four weeks

In both cohorts people with learning disabilities generally got on well with the people they lived with (>50% in all four instances), regardless of whether they lived with their family or other people with learning disabilities. However, a smaller proportion of people with learning disabilities in Cohort 2 seemed to get on well with people they live with (59%) than in Cohort 1 (80%). It is important to note, however, that for Cohort 2 this was a family carer or staff member's perception, so it is not possible to make a direct comparison.

### 2.3.4. Visitor restrictions

Participants in Cohort 2 were asked about whether there had been any visitor restrictions where the person they support/care for lived. We have separated these into two groups: people who live with family, and people who live in other places. These data are presented in Figure 2.28 below.

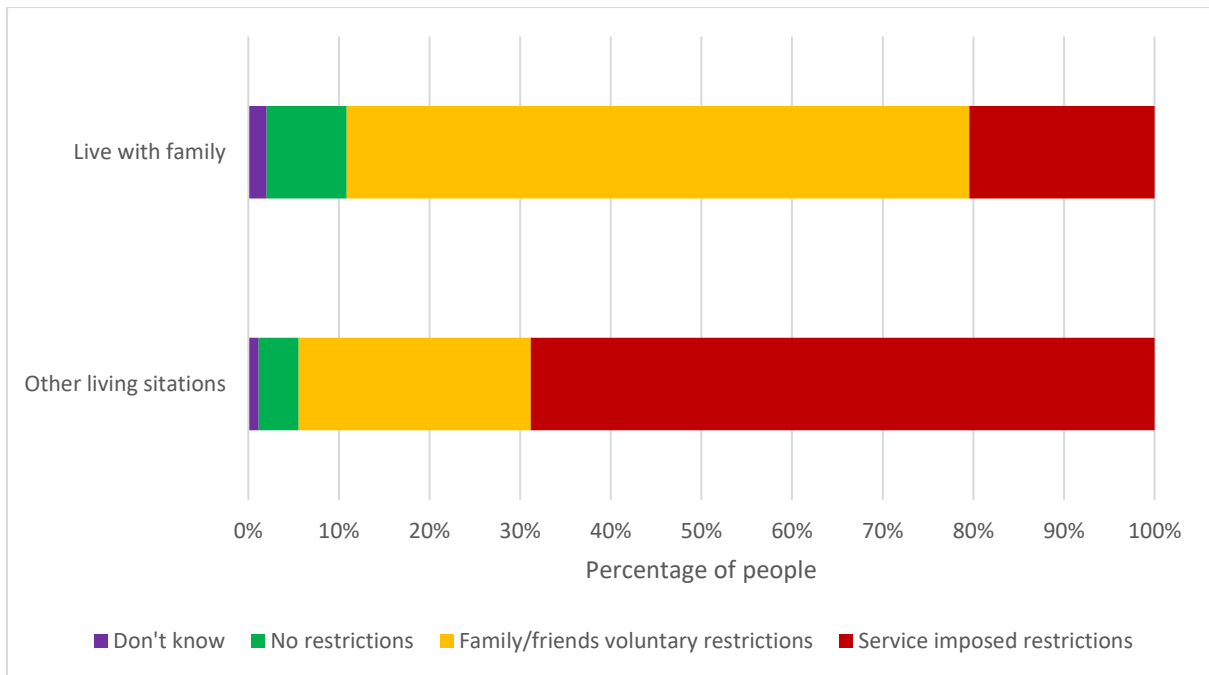


Figure 2.28. Have there been visitor restrictions to the home of the person you support/care for? (Cohort 2 only)

In Cohort 2, over 85% of people with learning disabilities in both groups had some form of visitor restrictions where they lived. For people with learning disabilities living with their families (n = 217), friends or family members most commonly imposed these restrictions (76%). In other living situations (n = 161), restrictions on visitors were typically imposed by the service provider (80%).

We asked participants in Cohort 2 some follow-up questions about visitor restrictions, including the extent of restrictions for family and friends, and for professionals. These data are presented in Table 2.14.



Table 2.14. Visitor restrictions for people with learning disabilities since the first lockdown in March 2020 (Cohort 2 only)

		<b>Cohort 2</b>
<b>Are they allowed access/visits from families and friends</b>		
	Full access	5%
	Restrictions on some occasions	19%
	Partial access	35%
	Only Key Worker family and friends	18%
	No access	20%
	Don't know	3%
<b>Restrictions on visits from professionals</b>		
	Full access	16%
	Restrictions on some occasions	18%
	Partial access	30%
	No access	28%
	Don't know	8%

At least a fifth of people with learning disabilities had not been allowed any visits from family members and friends (20%) and/or professionals (28%) since the first lockdown in March 2020. In Cohort 2, people with learning disabilities aged 45 and over were 3.3 times more likely to have had at least some access to visits from professionals, compared to those aged 44 and under ( $p = .02$ ).

We also asked about the impact that these restrictions had had on the people with learning disabilities being supported/cared for by participants in Cohort 2. These data are presented in Figure 2.29.

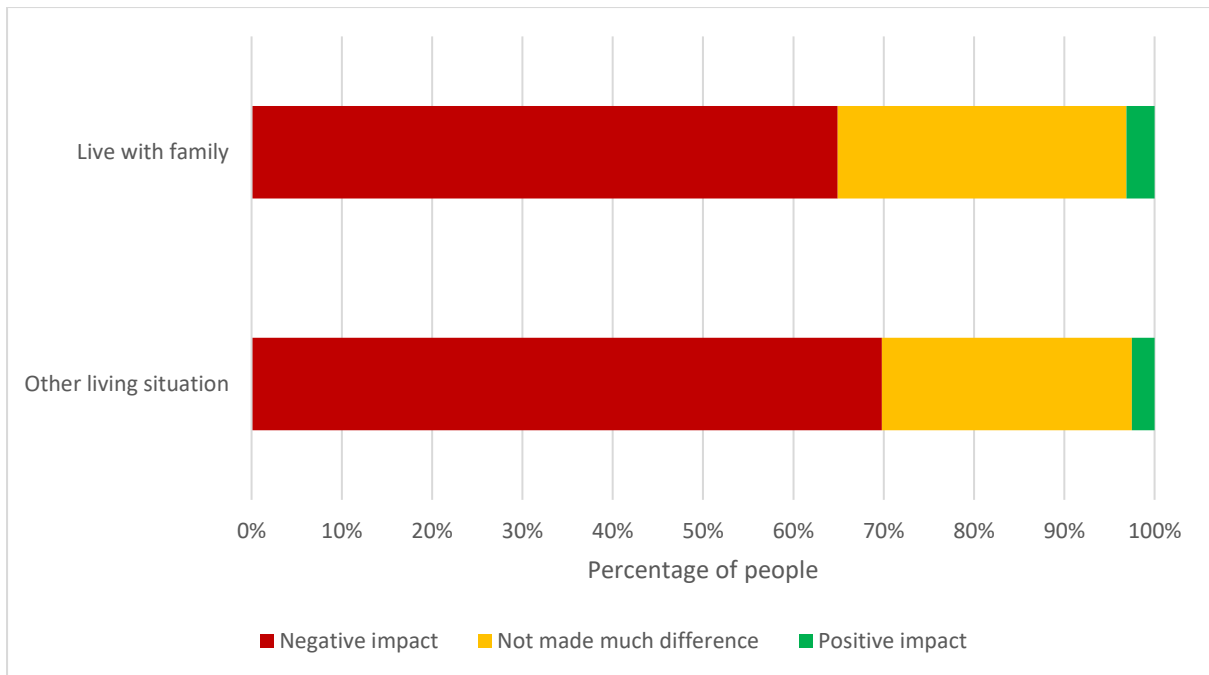


Figure 2.29. Have these restrictions on access/visits had an impact on the person you support/care for? (Cohort 2 only)

In Cohort 2, regardless of whether people with learning disabilities lived with family or in another living situation, 67% and 68% respectively were reported to have experienced a negative impact as a result of visitor restrictions. Some participants in Cohort 2 elaborated on the ways in which visitor restrictions had affected the person they support/care for. Some of these comments are presented in Box 2.4.

“My daughter became depressed and anxious when she was no longer allowed to visit the family home. She became very withdrawn, sleepy and reluctant to eat, drink and take her anti-convulsant medication.”

“He was used to family members and friends visiting and cannot understand why he can't see people in his own home or in their home.”

“My son is autistic and lives in his own world. Fortunately, he is quite happy at home, although even he misses social contacts.”

“My daughter has adapted to not seeing me (her mother) face to face indoors and only at a safe distance outdoors (no physical contact). This is because of the amazing team of professional carers who look after her.”

“She has now become totally used to us providing every bit of care and has become withdrawn to outsiders.”

“She is very close to her parents and not seeing them has been very hard for her. When restrictions eased she could see them if they wore PPE and kept their distance and this helped. But she would try and get closer to them and they would have to move away.”

“He became distressed and self-harmed.”

“At times my daughter feels that she has done something wrong that is making people stay away and that the virus is her fault.”

“Her behaviour has deteriorated and she has become violent towards her parents.”

“Dental problems with his gums for lack of specialist care.”

“He does nothing but wander up and down his accommodation all day with nothing to do and nowhere to go. Now spending a lot of time falling asleep with boredom. Lack of fresh air, lack of contact with society. Very depressed sometimes refuses to get out of bed.”

Box 2.4. Please describe the impact of visitor restrictions on the person you support/care for (Cohort 2 only)

Participants in Cohort 2 overwhelmingly described negative effects of visitor restrictions. The main effects were those of isolation, boredom, frustration, and confusion about why things had changed. Family carers reported that their family member with learning disabilities had increased reliance on them to perform all aspects of care. This was due to restrictions but, in some cases, it had led to the person with learning disabilities being reluctant to trust someone else. Generally, mental and physical health problems had reportedly continued to escalate

throughout the past year. A small number of participants in Cohort 2 reported that the person with learning disability was relatively happy to be in isolation.

### 2.4.5. Digital inclusion

With a move away from being able to see people, friends, family, and professionals face-to-face, we were interested to know what the digital inclusion of people with learning disabilities was like. We were particularly interested in knowing whether people with learning disabilities in both cohorts had access to the internet and a telephone from which to make calls. These data are presented in Table 2.15 below.

Table 2.15. Internet and telephone access and use for people with learning disabilities

	Cohort 1	Cohort 2
<b>Uses Internet at Home</b>		
Yes	92%	
Has internet but doesn't use	5%	
Doesn't have the internet	3%	
<b>Access to internet/telephone</b>		
Internet at home		66%
Device to use internet		57%
Telephone for calls		37%
Internet/phone to be used on their behalf		62%

Whilst almost all (92%) people with learning disabilities in Cohort 1 used the internet at home, this appeared to be more limited in Cohort 2 where just two-thirds of participants (66%) were reported to use the internet at home. In Cohort 1, people with learning disabilities aged 45 and over were 7.7 times less likely to use the internet than people with learning disabilities aged 44 and under ( $p < .001$ )

As well as knowing whether people with learning disabilities had access to the internet and a telephone for calls, we asked about whether any attempts had been made to scam or cheat people with learning disabilities in Cohort 1 out of money over the telephone or internet. These data are displayed in Figure 2.30.

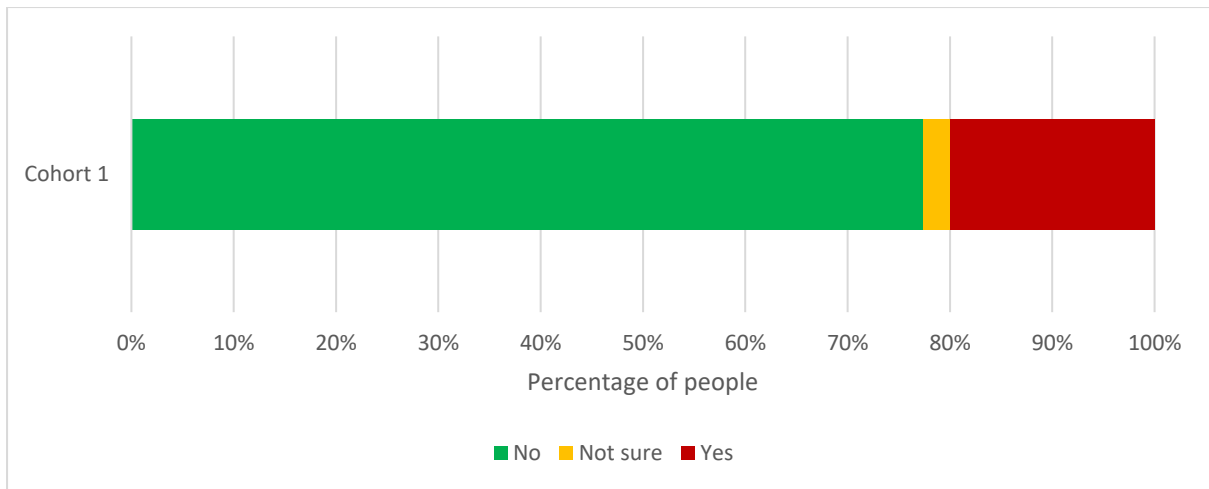


Figure 2.30. In the last four weeks, has someone tried to scam you/cheat you out of money over the phone or internet? (Cohort 1 only)

In Cohort 1, 122 (20%) of people with learning disabilities reported that someone had tried to scam/cheat them out of money over the last four weeks.

## **2.5. Sources of support**

In this sub-section, we report on questions about formal sources of support that people with learning disabilities in both cohorts had access to before and after the first lockdown in March 2020.

Of all the people with learning disabilities included in both cohorts, Table 2.16 reports how many were regularly receiving different formal supports before the first lockdown in March 2020.

Table 2.16. The percentage of people with learning disabilities who used different formal supports regularly before the March 2020 lockdown

	<b>Cohort 1</b>	<b>Cohort 2</b>
<b>Day services</b>	37%	59%
<b>Community activities</b>	87%	83%
<b>Further education</b>	17%	22%
<b>Going out with Personal Assistants/Support Workers</b>	51%	78%
<b>Respite/Short breaks away from home</b>	27%	38%
<b>Personal Assistants /Support Workers helping them at home</b>	56%	61%
<b>Social Worker visits</b>	37%	37%
<b>Professional contact by telephone/video call</b>	17%	19%
<b>Support from volunteers</b>	15%	10%

The following figures (Figures 2.31-2.39) present data about whether those people with learning disabilities who had received each formal support listed in Table 2.16 regularly before the March 2020 lockdown had received them since. People with learning disabilities who received formal supports regularly pre-lockdown reported using them less since the March 2020 lockdown.

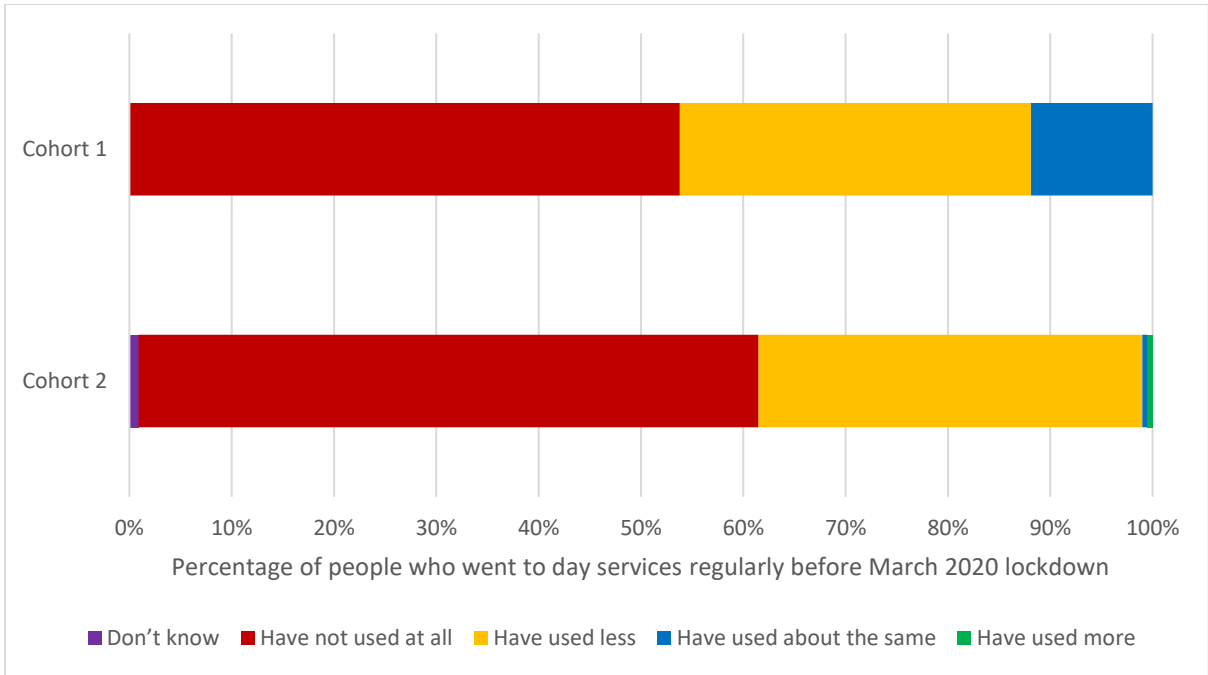


Figure 2.31. The percentage of people with learning disabilities who have gone to day services as much as before the March 2020 lockdown (Sample: Cohort 1 (n=237), Cohort 2 (n=212))

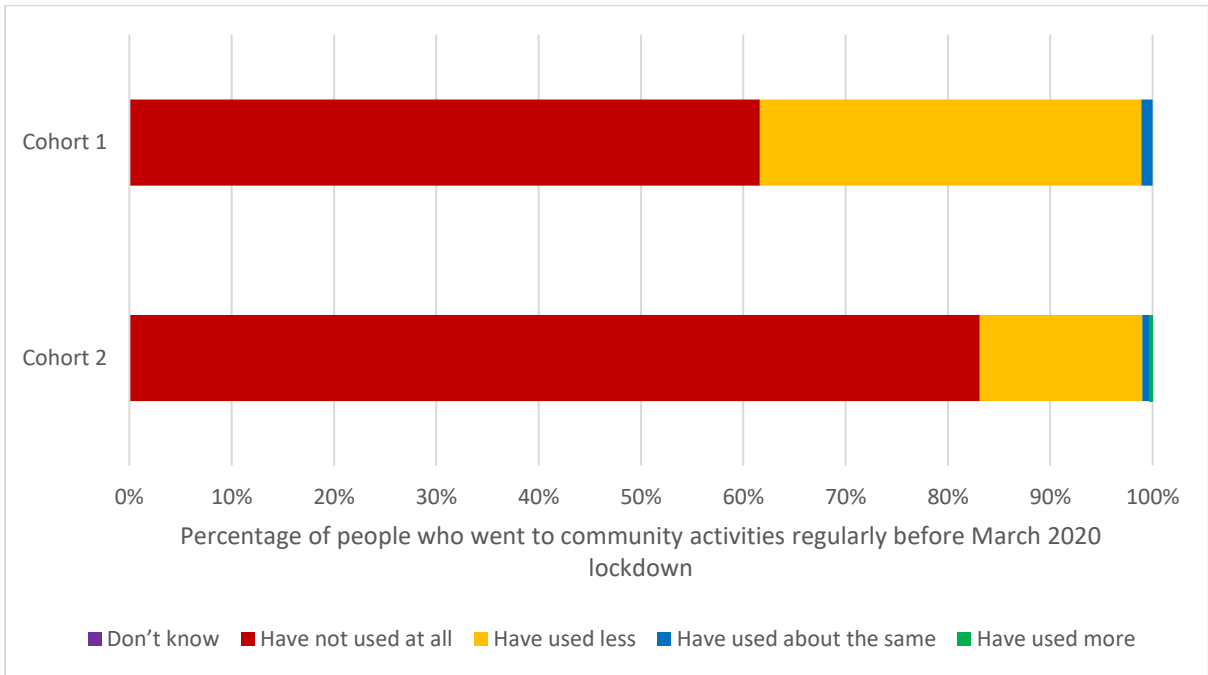


Figure 2.32. The percentage of people with learning disabilities who have gone to community activities as much as before the March 2020 lockdown (Sample: Cohort 1 (n=332), Cohort 2 (n=307))

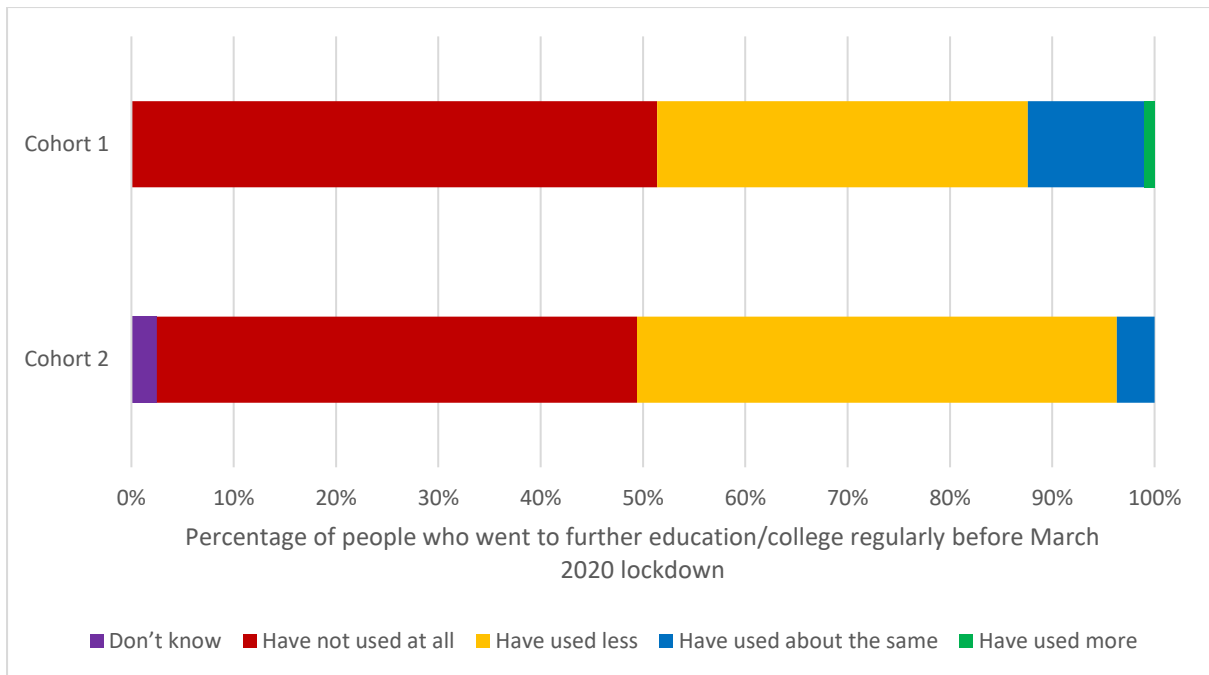


Figure 2.33. The percentage of people with learning disabilities who have gone to further education/college as much as before the March 2020 lockdown (Sample: Cohort 1 (n=78), Cohort 2 (n=85))

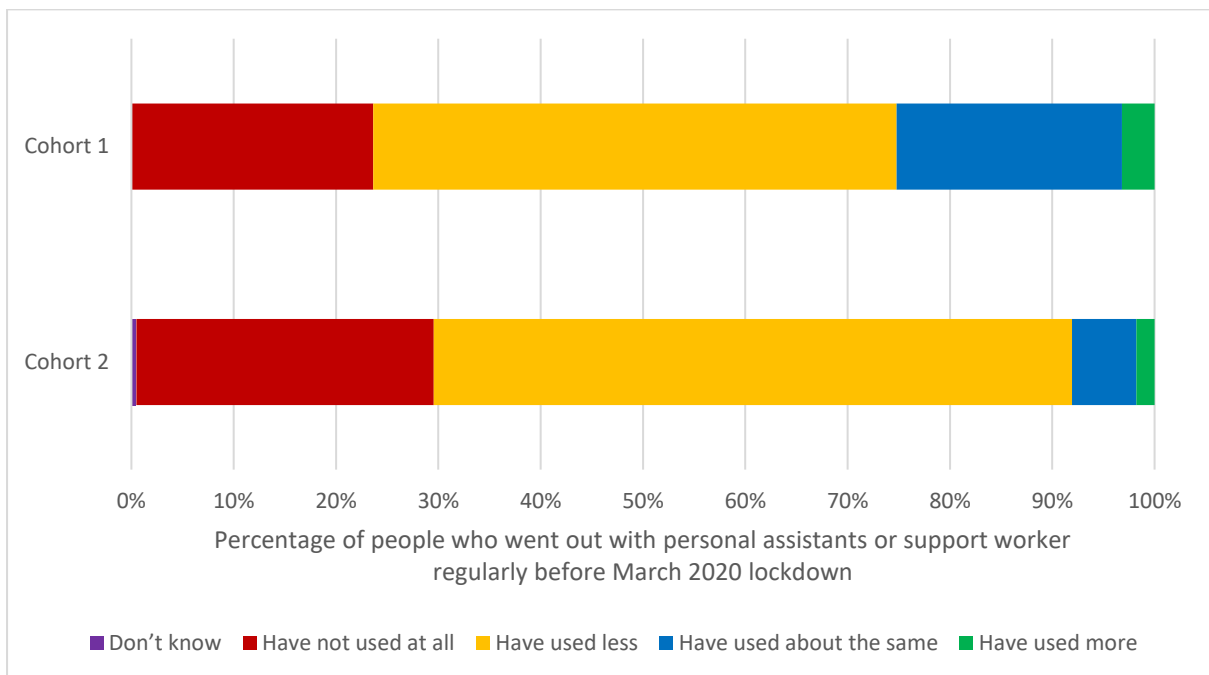


Figure 2.34. The percentage of people with learning disabilities who have gone out of the house with a personal assistant or support worker as much as before the March 2020 lockdown (Sample: Cohort 1 (n=174), Cohort 2 (n=272))



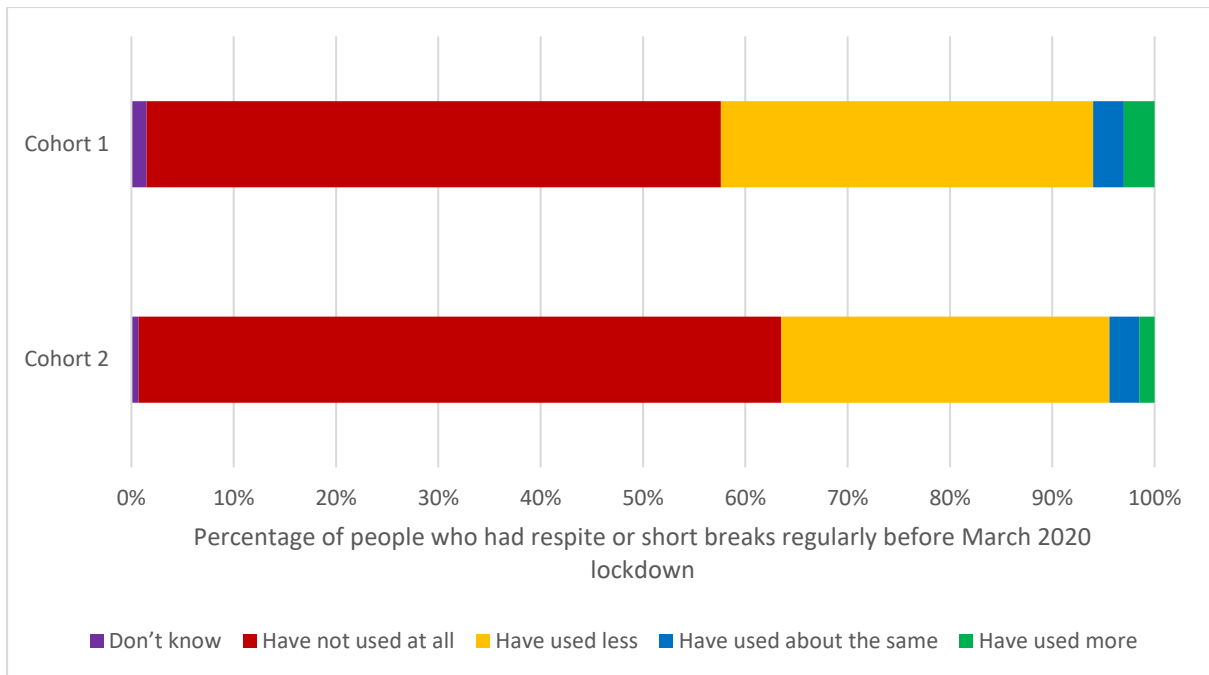


Figure 2.35. The percentage of people with learning disabilities who have had as many short breaks or respite as before the March 2020 lockdown (Sample: Cohort 1 (n=66), Cohort 2 (n=142))

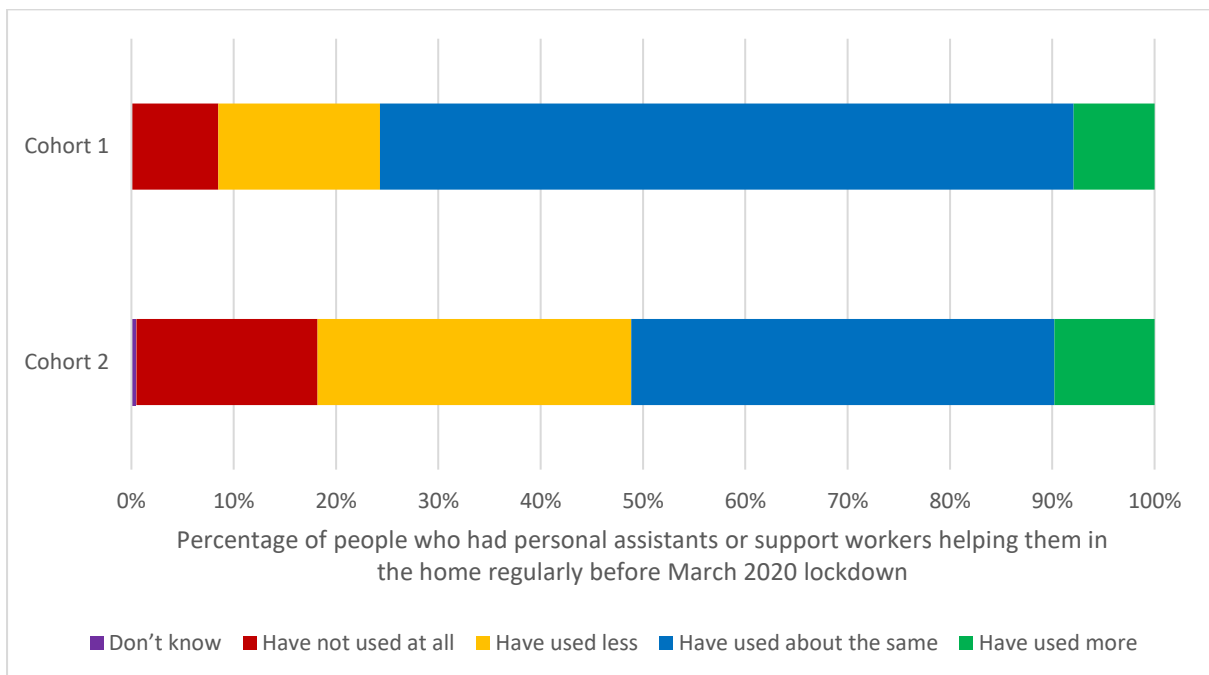


Figure 2.36. The percentage of people with learning disabilities who have had personal assistants or support workers helping them at home as before the March 2020 lockdown (Sample: Cohort 1 (n=177), Cohort 2 (n=214))

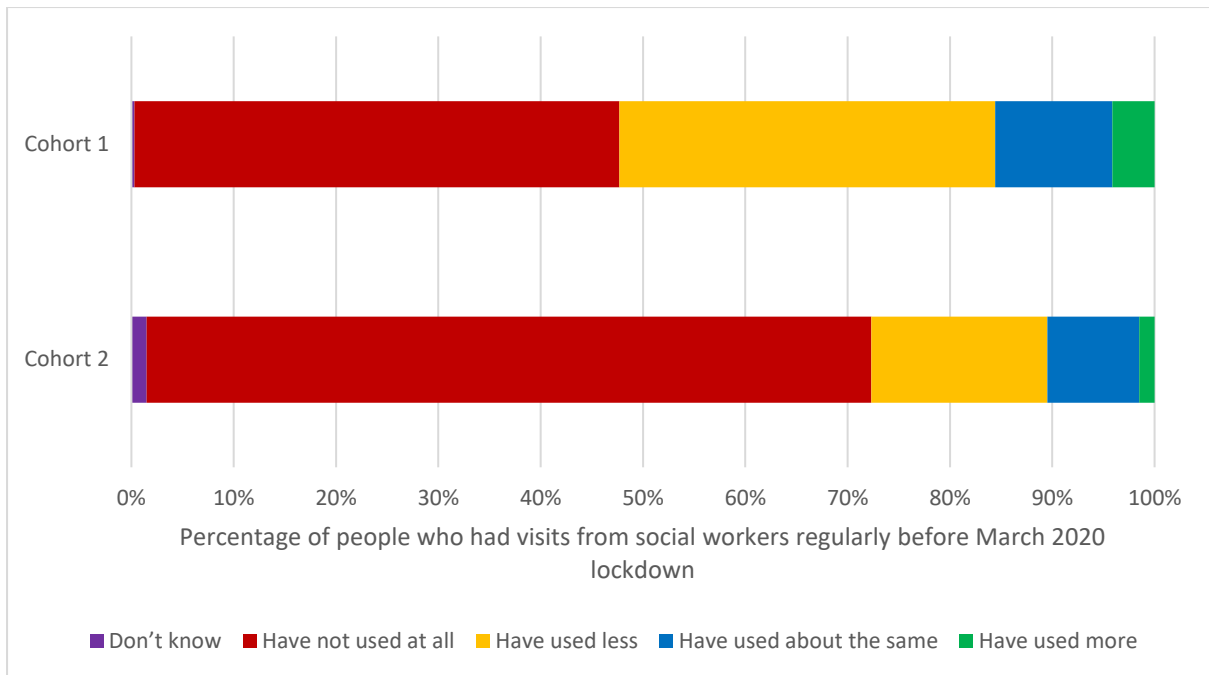


Figure 2.37. The percentage of people with learning disabilities who have received visits from social workers as before the March 2020 lockdown (Sample: Cohort 1 (n=123), Cohort 2 (n=134))

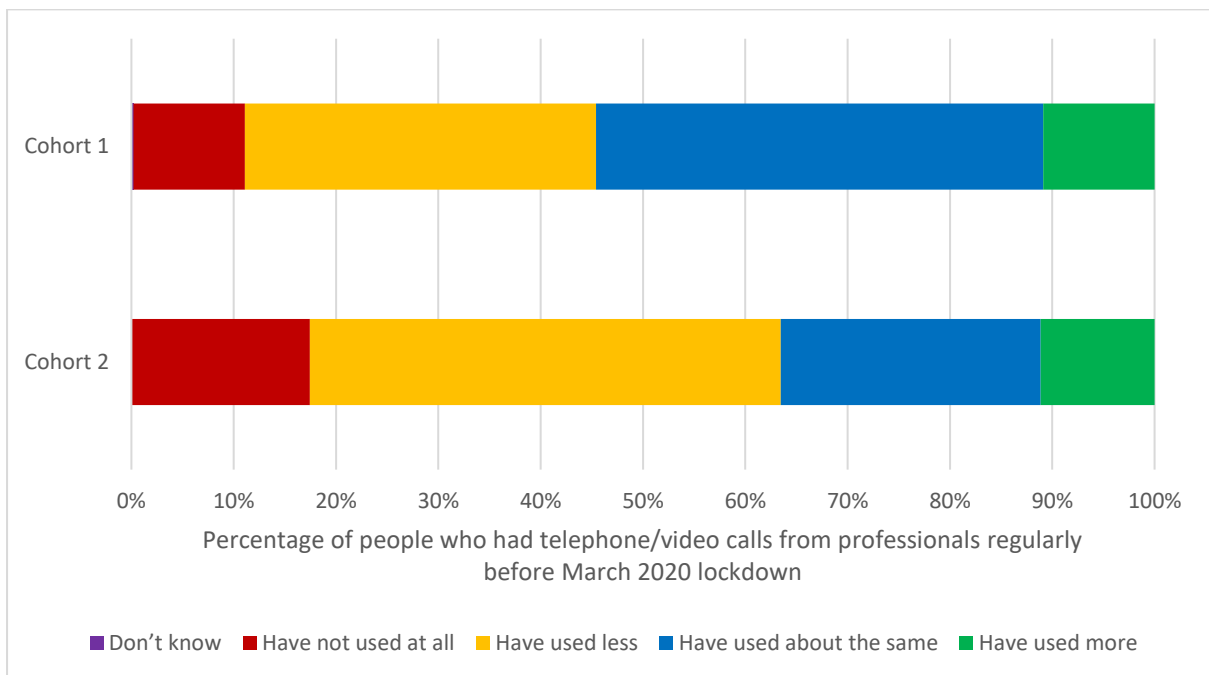


Figure 2.38. The percentage of people with learning disabilities who have got as much support from professionals like social workers / nurses / calling them by phone, computer or tablet rather than seeing them face to face (Sample: Cohort 1 (n=64), Cohort 2 (n=65))

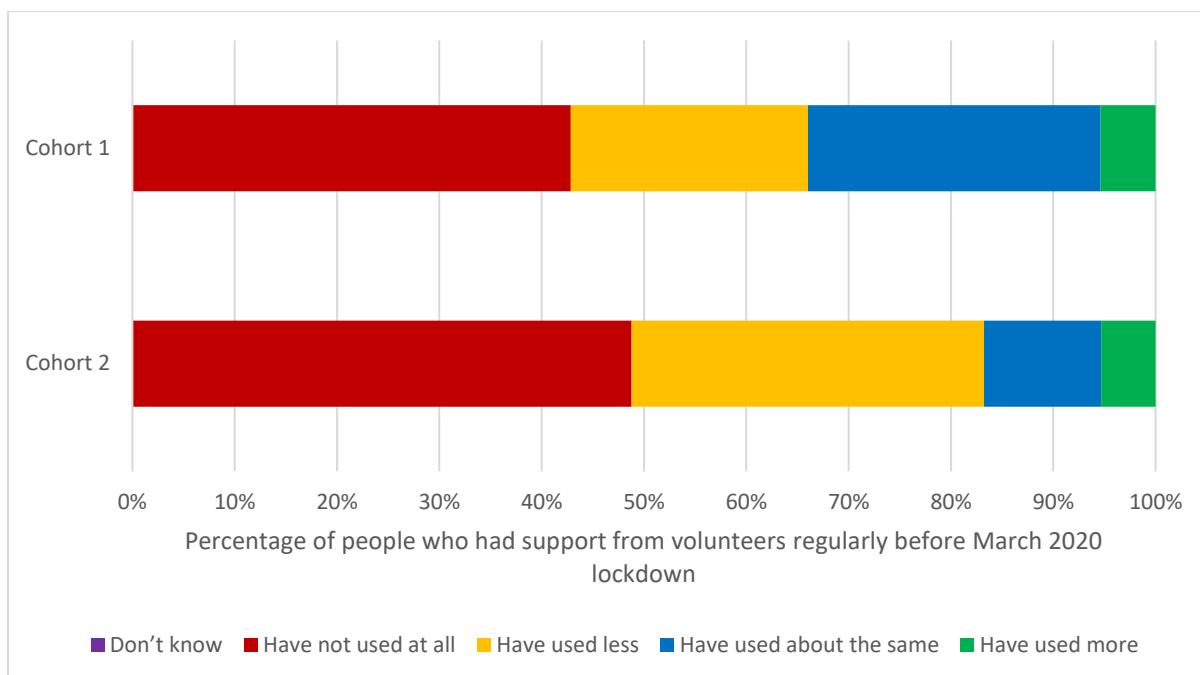


Figure 2.39. The percentage of people with learning disabilities who have got as much support from volunteers as before the March 2020 lockdown (Sample: Cohort 1 (n=56), Cohort 2 (n=38))

A substantial reduction in the amount of support received by people with learning disabilities was reported in both cohorts following the March 2020 lockdown. People with learning disabilities in Cohort 1 appeared to be slightly less severely impacted than Cohort 2. Yet, 99% of participants in Cohort 1 reported community activities had stopped completely or reduced by the time of the interviews (Dec 2020 – Feb 2021) and 92% of people reported short breaks/respice stopping completely or reducing post-lockdown. Carers of people with learning disabilities in Cohort 2 reported that 95% of people with learning disabilities have experienced a short breaks/respice stopping or reducing, whilst 98% reported day services stopping or reducing (compared to 89% in Cohort 1), and 99% reported that support for community activities had stopped or reduced since the first national lockdown in March 2020.

## **2.6. Living circumstances, employment, and money**

In this sub-section, we report findings from questions about the living circumstances, employment, and money of people with learning disabilities during the COVID-19 pandemic. These are:

- how people with learning disabilities are getting food,
- how people with learning disabilities are getting their medications,
- whether people with learning disabilities have access to outdoor space,
- about the reasons why people with learning disabilities are leaving their homes,
- about the employment of people with learning disabilities, and
- about the finances of people with learning disabilities.

### **2.6.1. Food**

Participants in both cohorts answered questions about how people with learning disabilities were getting food during the COVID-19 pandemic. The data from these questions are presented in Table 2.17.

Table 2.17. How people with learning disabilities are getting food

	<b>Cohort 1</b>	<b>Cohort 2</b>
<b>Through family</b>	40%	56%
<b>Shopping on their own</b>	31%	
<b>From the place they live in</b>		23%
<b>Delivered from supermarkets</b>	22%	17%
<b>Shopping with support/care worker</b>	22%	12%
<b>Through other people</b>		4%
<b>From support organisations</b>	12%	3%
<b>Through friends or neighbours</b>	3%	2%
<b>From a food bank</b>	1%	<1%
<b>Food parcels – they are shielding</b>	1%	1%
<b>Food parcels – person they live with is shielding</b>	<1%	1%
<b>Finding it difficult to get food</b>	1%	1%

Our data indicate that only 1% of people with learning disabilities in both cohorts were finding it difficult to get food. People with learning disabilities in Cohort 1 were much more likely to go shopping on their own or with the help of a support/care worker (53%) than those in Cohort 2 (12%). In both cohorts, participants were most likely to get food from their family members (40% and 56% respectively). Very few people in either cohort (1% or less) were getting food from a food bank.

We also asked participants in Cohort 1 about whether they had been hungry in the last week, but had not eaten, and these data are presented in Figure 2.40.

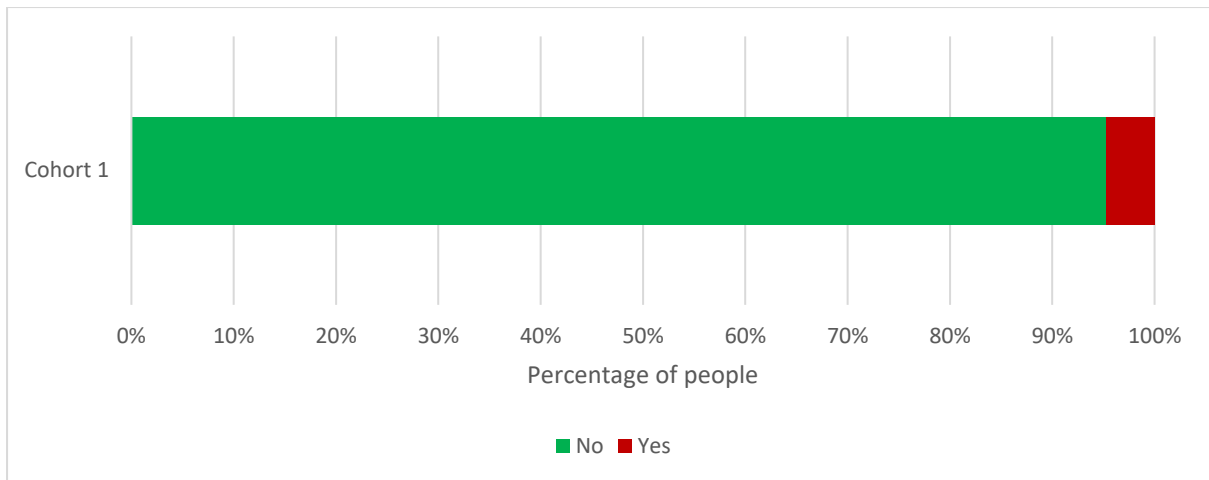


Figure 2.40. During the last week have you been hungry but not eaten? (Cohort 1 only)

Within Cohort 1, 32 participants (5%) reported being hungry during the last week but not eating.

### 2.6.2. Medications

In Cohort 1, 74% of people with learning disabilities and in Cohort 2, 81% of people with learning disabilities were taking medications. In Cohort 2, people with learning disabilities aged 45 and over were 2.7 times more likely to be reported to be taking medication, compared to those aged 44 and under ( $p = .03$ ). Table 2.18 displays data about how people with learning disabilities in both cohorts were getting their medicines.

Table 2.18. Obtaining medicines

	Cohort 1 (n = 477)	Cohort 2 (n = 294)
<b>Delivered from pharmacy/chemist</b>	38%	24%
<b>On own – from pharmacy/chemist</b>	28%	4%
<b>From family</b>	25%	53%
<b>With support – from pharmacy/chemist</b>	21%	13%
<b>From friends/neighbours</b>	1%	2%
<b>From the place they are living in</b>		16%
<b>Finding it difficult</b>	1%	1%
<b>Not getting medicines</b>		<1%

A very small number of people in both cohorts (1%) were finding it difficult to get their medicines, and less than 1% of people in Cohort 2 were not getting medicines. In both cohorts, it was relatively common for people with learning disabilities to receive medicines from family (Cohort 1 = 25%, Cohort 2 = 53%), or to have them delivered from the pharmacy or chemist (Cohort 1 = 38%, Cohort 2 = 24%). People with learning disabilities in Cohort 1 were more likely to get their medication on their own (28%), compared to Cohort 2 (4%)

### 2.6.3. Access to outdoor space

We asked participants in both cohorts about whether people with learning disabilities had easy access to outdoor space, and these data are presented in Table 2.19.

Table 2.19. Access to outdoor space for people with learning disabilities

	Cohort 1	Cohort 2
<b>Current home has outdoor space</b>		
Private garden	61%	76%
Shared garden	25%	15%
Balcony	2%	1%
Rooftop garden/terrace		1%
Other outdoor space	3%	6%
No	6%	4%
<b>Access to outdoor space (within 10-15 minute walk)</b>		
Yes	87%	83%
No	11%	17%
Don't know	2%	1%

The vast majority of people with learning disabilities had access to a private or shared garden in Cohort 1 (86%) and Cohort 2 (91%).

### 2.6.4. Leaving the house

We also asked about the reasons people with learning disabilities left their home during the week before the interview or survey, and given the different restrictions during our data collection period, we have separated this into two sub-samples for this question. These are: (1) data collected in December 2020, before lockdown measures were introduced in all four UK nations, and (2) data collected in January and February 2021, when lockdown measures were in place in all four UK nations. The reasons people with learning disabilities in both cohorts left their houses are presented in Figures 2.41 and 2.42.

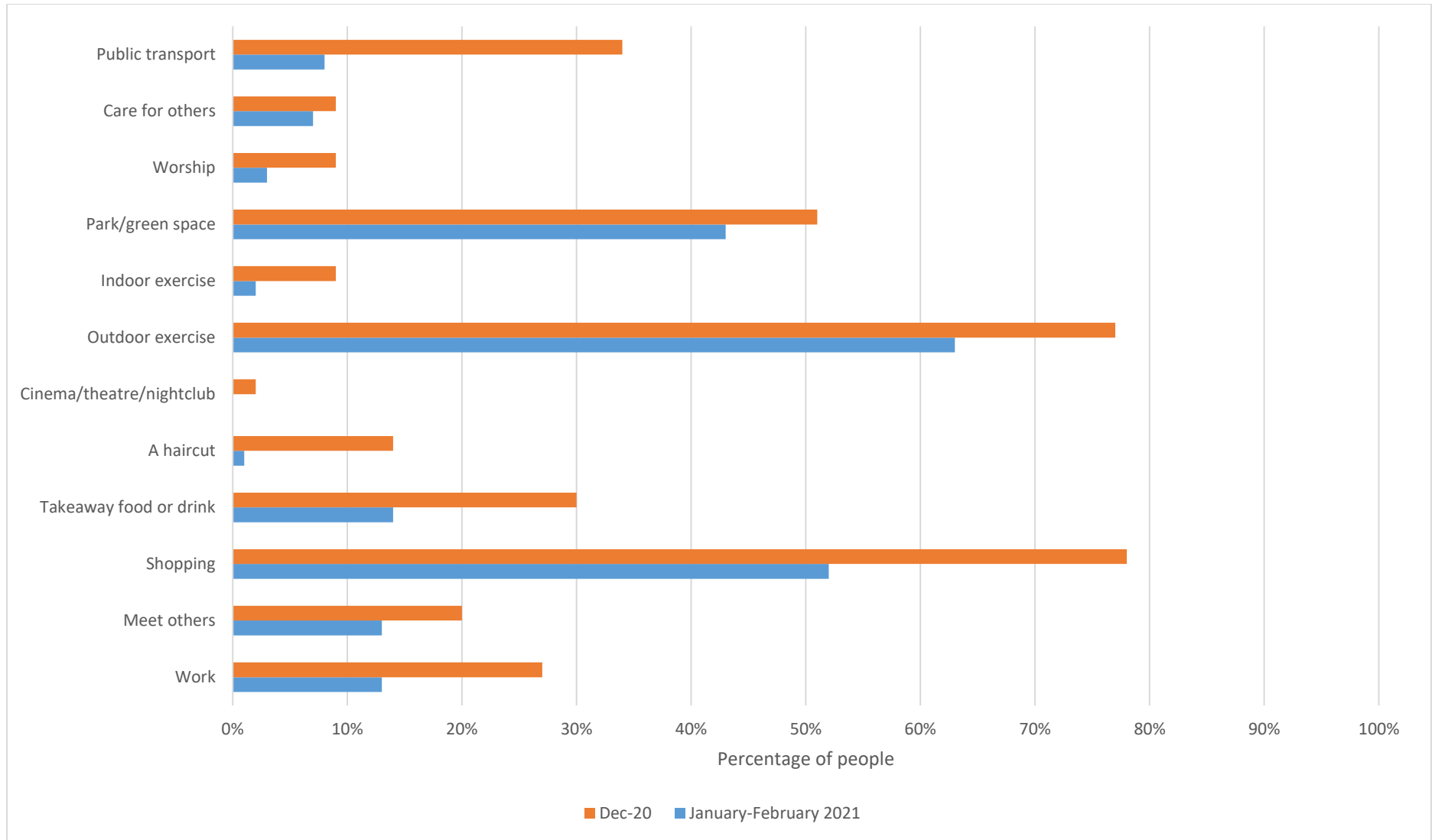


Figure 2.41. Reasons that people with learning disabilities left their house in the last week, reported by when they completed the interview (Cohort 1 only)

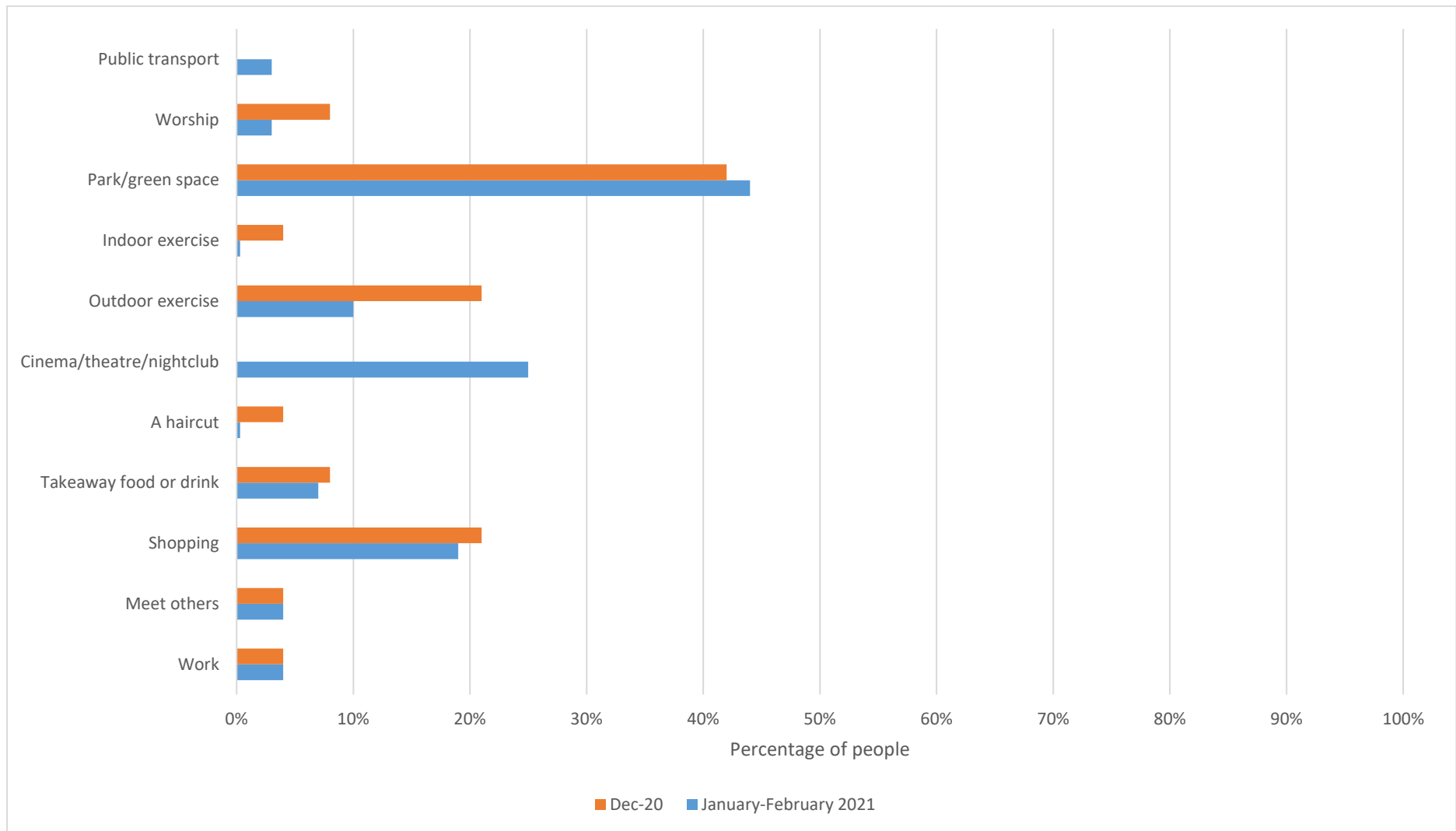


Figure 2.42. Reasons that people with learning disabilities left their house in the last week, separated by when they completed the survey (Cohort 2 only)



In December 2020, the most frequent reasons for people with learning disabilities leaving the house were to go to an outdoor park (Cohort 1 = 51%, Cohort 2 = 42%), shopping (Cohort 1 = 78%, Cohort 2 = 21%), and for outdoor exercise (Cohort 1 = 77%, Cohort 2 = 21%). People with learning disabilities were less likely to leave their house for any of the listed reasons in January and February 2021, during the lockdowns in all four UK nations, including outdoor exercise (Cohort 1 = 14% decrease, Cohort 2 = 11% decrease).

## 2.6.5. Employment

In Cohort 1, 198 people with learning disabilities (32%) reported that they had a paid job before the start of the first lockdown in March 2020. In Cohort 2, 15 participants (5%) reported that the person they support/care for had a paid job before the start of the first lockdown in March 2020. Table 2.20 presents data about what has happened to these paid jobs since March 2020.

Table 2.20. What has happened to your paid job since the first lockdown in March 2020?

	<b>Cohort 1 (n = 198)</b>	<b>Cohort 2 (n = 15)</b>
<b>Still working</b>	53%	29%
<b>Furloughed</b>	23%	36%
<b>Job being held (not furloughed)</b>	11%	29%
<b>Don't have a job anymore</b>	12%	7%
<b>Got another job</b>	2%	0%

Of the people with learning disabilities in Cohort 1 who had a job before the March 2020 lockdown (n=198), 88% were still in employment (still working, furloughing, or with their job held for them) during this Wave of the study. For Cohort 2, the majority of the 15 people with learning disabilities who previously had a job were still in employment when their carers were interviewed.

We also asked about volunteer work. In Cohort 1, 307 people with learning disabilities (50%) reported that they had volunteer work before the start of the first lockdown in March 2020. In Cohort 2, 56 participants (16%) reported that the person they support/care for had a volunteer job before the start of the first lockdown in March 2020. Table 2.21 presents data about what has happened to these volunteer jobs since March 2020.

Table 2.21. Volunteer work since the first lockdown in March 2020

	<b>Cohort 1 (n = 307)</b>	<b>Cohort 2 (n = 56)</b>
<b>Still have volunteer job</b>	35%	17%
<b>Still have volunteer job – not currently working</b>	46%	48%
<b>No volunteer job</b>	19%	35%

In Cohort 1, 81% of people with learning disabilities who did volunteer work before the March 2020 lockdown had kept their volunteer role during this wave of the study,

even if they were not currently working. In Cohort 2, a smaller percentage (65%) of people with learning disabilities had kept their volunteer role post-lockdown.

### 2.6.6. Money

Participants in both cohorts were asked about finances during the COVID-19 pandemic. These questions included whether people with learning disabilities had more or less money to spend, whether there had been any changes to benefits, and whether it had been easier or harder to pay household bills since the first lockdown in March. These data are presented in Figures 2.43-2.45.

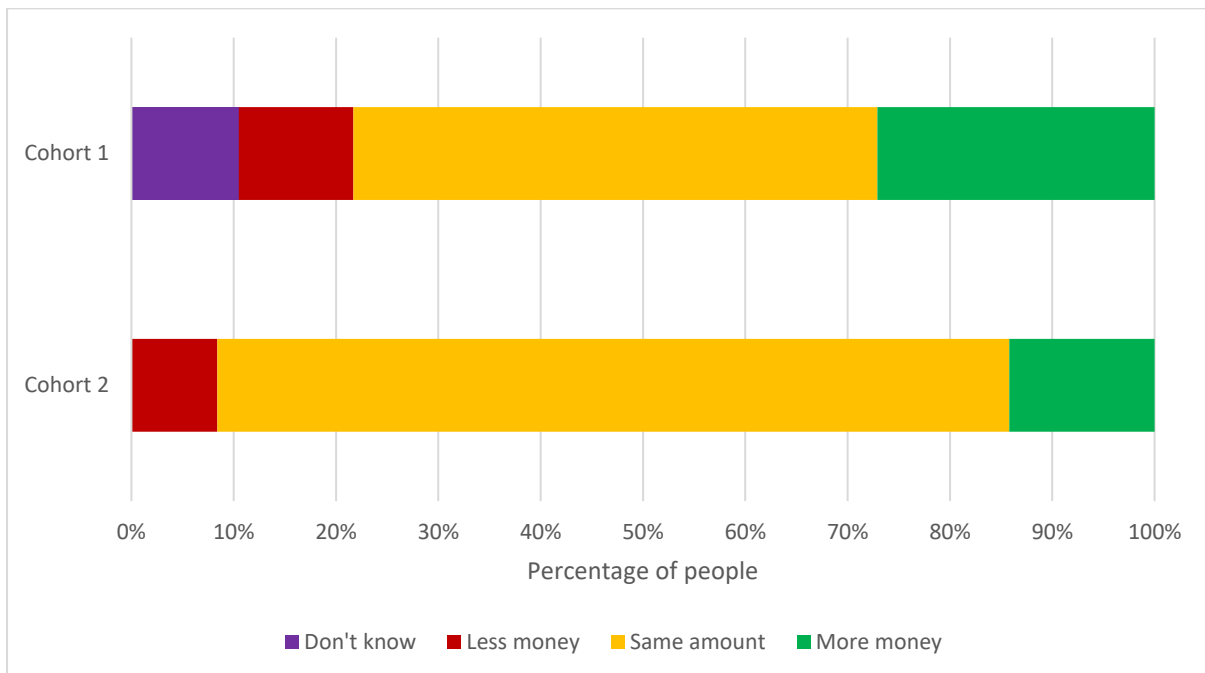


Figure 2.43. The amount of money people with learning disabilities have to spend compared to before the first lockdown in March 2020

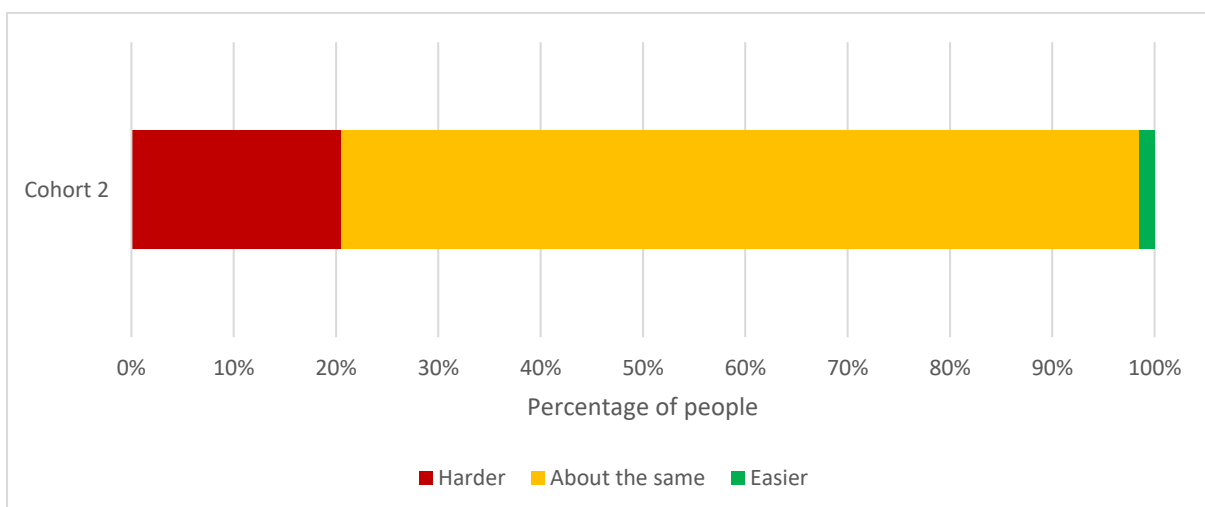


Figure 2.44. Has it been easier or harder for the household bills to be paid where the person you support/care for lives than before the start of the first lockdown in March 2020? (Cohort 2 only)

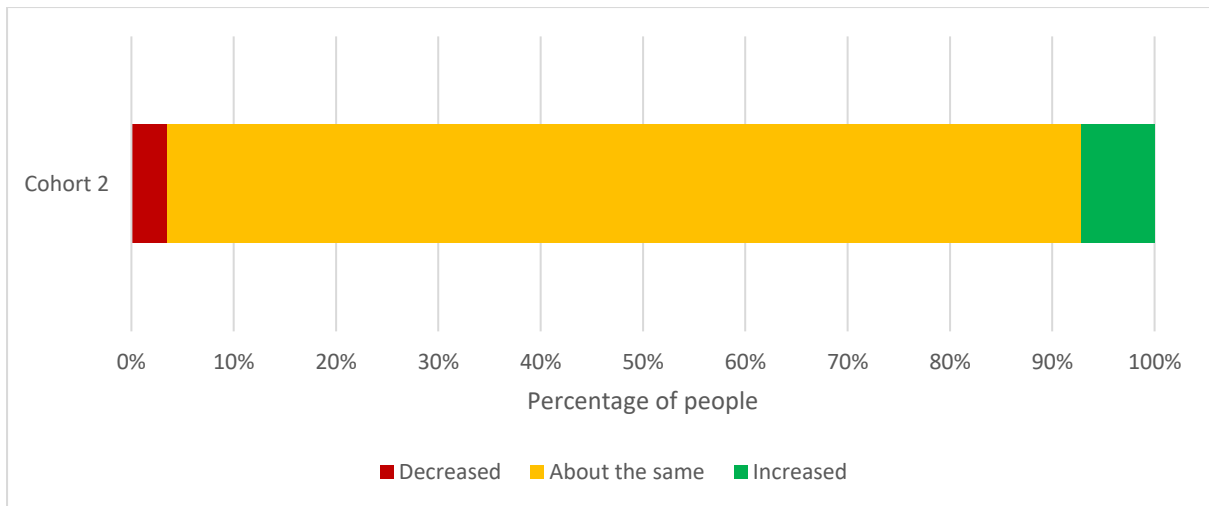


Figure 2.45. Has the amount of benefits the person you support/care for get changed the start of the first lockdown in March 2020? (Cohort 2 only)

Most people with learning disabilities in Cohort 1 (51%) have the same amount of money to spend now than they did before the first lockdown in March 2020, compared with 78% of people with learning disabilities in Cohort 2 who have the same amount of money to spend now. In Cohort 2, people with learning disabilities living with their family were 2.3 times more likely to be reported to be finding it harder to pay household bills following the first lockdown in March 2020, compared to people with learning disabilities who lived elsewhere ( $p = .01$ ).

## **2.7. COVID-19 experiences**

### **2.7.1. Cohort 1**

In Cohort 1, we asked people with learning disabilities some open-ended questions about their lives under COVID-19: their biggest worries, things that had been good, and what would make their lives better right now. Some of the responses to these questions are presented in Boxes 2.5-2.7 below.

“Catching it and then passing it on to my family because they have health problems - I don't want to pass it.”

“That it will go on without end and that the vaccine might not make it go away.”

“I am worried about the effect on the economy and people's wellbeing.”

“That I go into hospital with the virus and I don't want to die, my friend died and he was only 42.”

“Waiting too long for the vaccine. Why are people with LD so far down the list?”

“Not knowing government guidelines - all the changes.”

“People sticking to the rules - if people don't stick to the rules it will take us longer to go back to normal.”

“Because it's been going on for such a long time now I worried about whether I'll have my paid job back when it's all over and how soon I'm able to see my friends, my partner and family again”

“Nervous about things going back to normal as not used to being around lots of people. It feels like it would be very scary.”

“Not seeing my fiancé, I really miss him.”

“I lost my grandparents and the coronavirus affected the grieving process.”

“Being at home alone and not seeing friends and families.”

“I'm more concerned about dying from the virus and I'm worried if I'll be able to go back to my job, attend gym and see my friends & family.”

“It scares me a bit, all the people dying on the telly.”

Box 2.5. What are your biggest worries about COVID-19? (Cohort 1 only)

When asked about their biggest worries, many people in Cohort 1 said that they were most worried about catching COVID-19, or their families catching it. People

were more concerned about the people they loved rather than themselves; this is reflective of the findings from the Pandemic Anxiety Scale in [section 2.3](#).

Other areas of concern were whether their lives would ever return to normal, and what the longer-term effects of COVID-19 would be on wellbeing and jobs, in particular. People spoke of the vaccine, questioning whether it would work, if people would take it, and why they had not been offered it already. Many people expressed concern about the behaviour of other people who were not adhering to COVID-19 restrictions.

“I like staying at home with mum, spend more time together.”

“I have lost weight since the start of lockdown.”

“I met my girlfriend through my new company, on a conference. I got closer to my staff here as well, they have been fantastic.”

“Spent more time with my family in the house.”

“I feel lucky that I have been safe. Getting a bit more money is good – we are going to get a new settee! And I have made more cakes.”

“Having to adjust to a major life change. My ability to have coped with an unpredictable, fast-changing situation. It's given me confidence and awareness.”

“Social network has increased - made a lot of new friends through online groups and going to more online events (party nights and stay in touch groups).”

“My IT skills are better.”

“I've discovered that I'm quite a homebody, I like my own space, I like quiet time. I enjoy my own company”

“Learnt how to work from home, and how to use zoom which has also helped me stay in touch with people outside work”

“Gotten closer with my son.”

Box 2.6. Has anything good happened in your life because of COVID-19? (Cohort 1 only)

When asked about whether anything good had happened in the lives of participants because of COVID-19, many people said that nothing positive had happened. Of those who said that something positive had happened, this mainly centred around people being able to spend more time with their family or people they lived with, or making lifestyle changes (e.g., losing weight, exercising more, stopping taking drugs, or reducing smoking, or drinking alcohol).

Some people also said that they had been able to improve their technology/digital skills that have helped them to stay in touch with other people and/or do their jobs

from home. Others reflected on the changes to the way they see themselves, for example, being more at ease with their own company or gaining self-confidence.

“To be able to access the community and services to help my mental health.”

“Being able to see my family and my friends in person.”

“The virus is gone so can get back to normal life.”

“The rules being in easy read - this would make it better to understand. People with disabilities need to know the rules so they can understand.”

“Getting a job with more hours because two hours a week is not enough and also meeting people and make more friends because I am not making friends at work or in education my age.”

“I haven't seen my mum and dad for months because of the virus - seeing them would make my life better.”

“A holiday with sunshine.”

“If there was someone who could talk to me and explain the changes in the pandemic, I do not understand the news. I do not understand Boris's speeches.”

“The pubs opening. To have a beer and get something to eat with my friends.”

“Getting back to my day service. To meet with my girlfriend sometime soon - I would like to see her again.”

“The vaccine is what I'm waiting for.”

“If I found a job and got employed and found something useful to do with my time, or get back into education.”

Box 2.7. What would make your life better right now? (Cohort 1 only)

When asked about what would make their lives better right now, participants responded that if COVID-19 went away, or everyone got the vaccine, this would make their lives better. Other responses included spending more time with family and friends, going out to do different things, to get back to work, or have increased hours at work, and going on holiday. There were also calls for Easy Read information to be made available as some people reported that they found government and NHS information to be difficult to understand.

### **2.7.2. Cohort 2**

We also asked participants in Cohort 2 about the lives of the people they support/care for, including what their life has been like during the pandemic, any

positives that have happened because of the COVID-19 pandemic, and what would make their life better. Selected responses are presented in Boxes 2.8-2.10 below.

“Very restricted and stressful, though on-site carers have been good. The lockdowns have worried her enormously, especially when not able to see family and friends. The first lockdown was especially traumatic and she was very distressed.”

“The person supported has enjoyed more 1 to 1 support and attention. She is more relaxed than before but also demanding.”

“My son has massively suffered in losing his routines and his normal interaction with life and people. I have had to put him on risperidone in order to mitigate his extremely challenging behaviour and have had to do so without the required assessment and support.”

“His life has shrunk to four walls again with the lockdown. In between lockdowns he has been able to go for walks.”

“She has started to lash out and hit her mum and dad and now is under a behaviour specialist and social worker visits when not in full lockdown as she lives in Wales.”

“Limited in scope but safe, like a very extended holiday at family home. Not really interested in general conversation but asks many questions and seeks explanations. Frequently talks about plans in the future.”

“In many ways, better—all the things that were causing distress and anxiety (including going to respite) pre-pandemic have stopped, and he has benefitted from the consistency of being at home, engaging in his special interests.”

“She appears to be oblivious but I worry she isn't - she has not done any activities outside her home since March and stayed with staff at Christmas rather than coming home”

“She nearly died because [the hospital] was so worried about "COVID Pathways" an otherwise healthy young woman nearly died from tooth decay they WOULDN'T treat.”

Box 2.8. What has life been like for the person you care for/support during the pandemic? (Cohort 2 only)

According to the participants in Cohort 2, the people with learning disabilities who they cared for/supported had overwhelmingly negative experiences during the pandemic. Some common responses were that they have found lockdown to be boring, lonely and isolating. Other participants reported that the physical and mental health of the person they support has deteriorated and that they are displaying behaviours that are challenging for family carers/paid support staff (e.g., harming themselves or others).

“No but I’m grateful for the way his employer has treated him the same as everyone else in the company.”

“We’ve had the opportunity to work on home-based skills and develop some independence. Also a realisation (on our part, as carers) that the day service previously attended was perhaps not the best placement.”

“If you could ask my son, he would probably say yes - he likes being able to sleep longer and not having to go to school/somewhere else.”

“He has learned how to video chat with friends.”

“Our friends and community raised £7000 so we could get an electric wheelchair bike. He is having amazing outdoor experiences on it. Whole family now cycle together.”

“Her mental health has actually improved as she now has a constant, regular team of carers who she has grown very close to.”

“Better diabetes control due to consistent care and monitoring.”

“He got better and survived being on a COVID ward.”

“My brother’s staff team say staying at home have given them a deeper understanding of him - how he communicates, his preferred ‘pace’ of life and their relationships are even more meaningful.”

“He has had his COVID vaccination.”

“We have determined the best way to communicate with him.”

“Yes, we have all spent lots of time together as a family and enjoyed quality family time together.”

“No, I wouldn’t say anything good has happened because of the situation. More that we are making the most of a bad situation by adapting. But it isn’t better than before.”

“She has lost some weight and has become more friendly with another resident of the care home.”

Box 2.9. Has anything good happened in the life of the person you support/care for because of the coronavirus situation? (Cohort 2 only)

Generally, participants in Cohort 2 reported that nothing good had happened in the life of the person that they support/care for because of COVID-19. For those where there were some positives to come out of COVID-19, common responses were that they were able to spend more time at home together and had been spending more time focussing on key life skills (e.g., cooking).



The slower pace of life was also appreciated by some, with a realisation that perhaps routines were too full pre-lockdown and that they had now been able to spend more time with the person they support/care for, learning about their preferred methods of communication, for example. A few participants reported that the health and/or well-being of the person they care for/support had improved (e.g., lost weight, stopped eating as much junk food, fitness improved).

“My son is locked up in an institutional setting, which harms rather than heals, and which the pandemic has just made worse.”

“He needs to lose weight, he's put on loads since March which isn't helping his back or knee replacement.”

“A break from us as her carers probably! More social interaction with friends/family. Some online activities that she could engage with on her own - tailored to her interests and ability.”

“Can't think what would make any real difference other than the medical procedures she should have had that have been postponed being carried out sooner than later. She is suffering to a degree as direct effect of this.”

“For his day centre to open and for me to have more energy to care for him to my fullest ability.”

“Going back to the day centre. They would then be able to have social interaction with peers and have a structure to their day with activities which provide them with learning and fun.”

“To be vaccinated as soon as possible and for him to then not have the fear of catching this awful condition and to get out and meet with family and friends again.”

“To physically see the ones she loves, not just through a carers' phone screen.”

“Aside from the eradication of COVID, the behaviours of those in the general public being mindful of the higher risk of COVID to people with additional needs and taking responsibility for maintaining strict social distancing. It is a lot harder to move off paths for people with support needs, in a wheelchair etc.”

“The end of the pandemic!”

“His weekly routine to return to how it was, being able to attend community activities, swimming, cinema.”

“Been able to see her friends who she really misses.”

Box 2.10. What would make the life of the person you support/care better right now? (Cohort 2 only)

When participants in Cohort 2 were asked about what would make the life of the person they support/care for better, there were several common themes. These were: having more in person social contact with their friends and family, being able to access day centres and community activities, and getting a COVID-19 vaccine.



## **Chapter 3: Family carers/paid support staff and the COVID-19 pandemic: Results from Cohort 2 participants**

In this part of the report, we describe the results of questions for participants in Cohort 2 that related specifically to them as family carers or as paid support staff, covering COVID-19 information and rules, and the health and well-being of family carers and paid support staff.

### **3.1. COVID-19**

We asked participants in Cohort 2 about COVID-19 information and rules, in questions that were similar to those presented in [section 2.2.1](#) for participants in Cohort 1. The first of these was about how easy it was for family carers and paid support staff to find accurate information about how COVID-19 affects them. These data are presented in Figure 3.1.

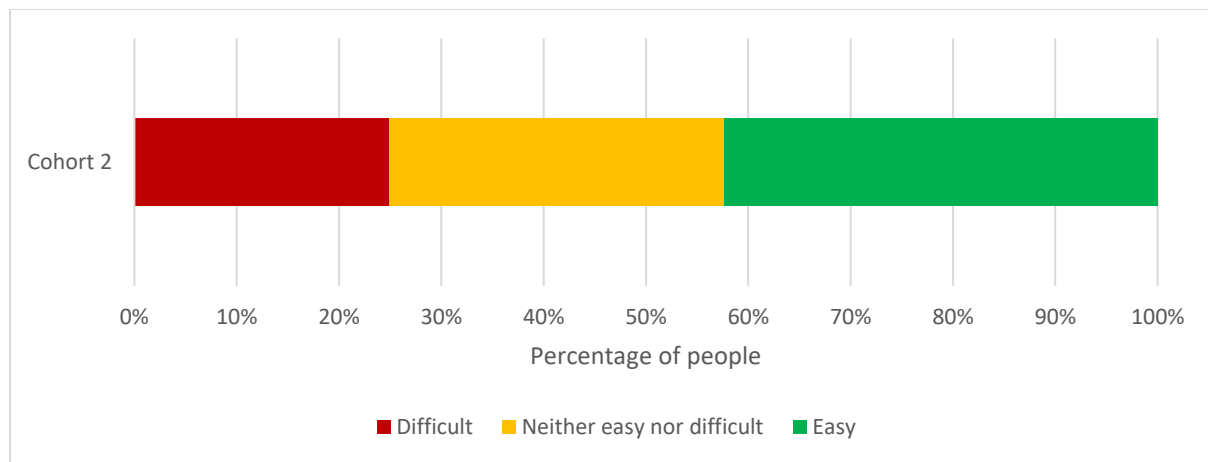


Figure 3.1. How easy has it been for you to find accurate information about how COVID-19 affects you as a family carer or paid support worker? (Cohort 2 only)

From this figure, we can see that only 43% of people in Cohort 2 found it easy to find accurate information about COVID-19.

As the rules were ever-changing, we asked participants about how they found out about changes to COVID-19 rules and information. Participants in Cohort 2 were asked to answer from their own perspective, rather than as a proxy for the person they support/care for. Participants were asked to select all the ways they found information about COVID-19 rule changes. These data are presented in Figure 3.2.

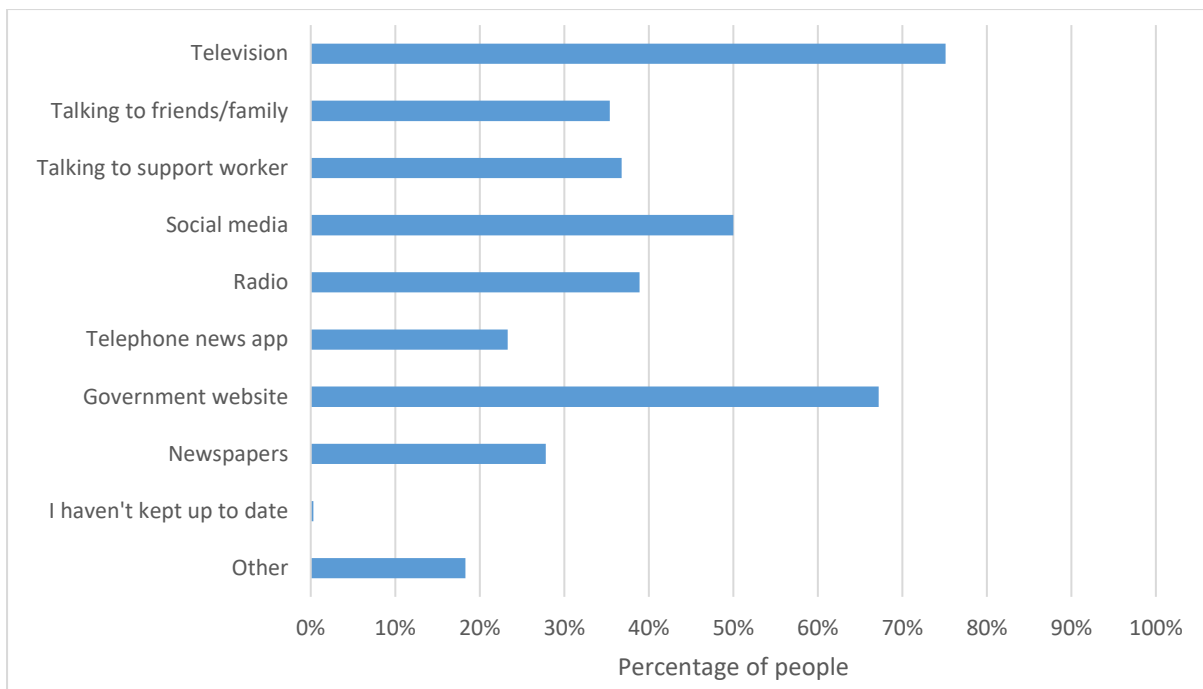


Figure 3.2. How do you find out about changes to COVID-19 rules/information? (Select all that apply) (Cohort 2 only)

The ways in which people with learning disabilities (Cohort 1, presented in [section 2.2.1](#)) and family carers/paid support staff (Cohort 2) found out about changes to COVID-19 rules and information differed. Television was the most popular means of finding out about changes to COVID-19 rules and information (79% in Cohort 1, 75% in Cohort 2), but family carers/paid support staff in Cohort 2 were more likely to use government websites (67%) and radio (39%) compared to people with learning disabilities in Cohort 1 (12% and 16% respectively).

### **3.2. Health and wellbeing**

We also asked about the health and wellbeing of family carers and support staff during the COVID-19 pandemic. There were some additional data collected about the health and wellbeing of family carers and support staff, but these data will be reported in reports from Wave 2 onwards when we are able to examine changes over time.

We asked specifically about what effect their caring role had had on their health and wellbeing in the last four weeks, and these data are presented in Figure 3.3 below.

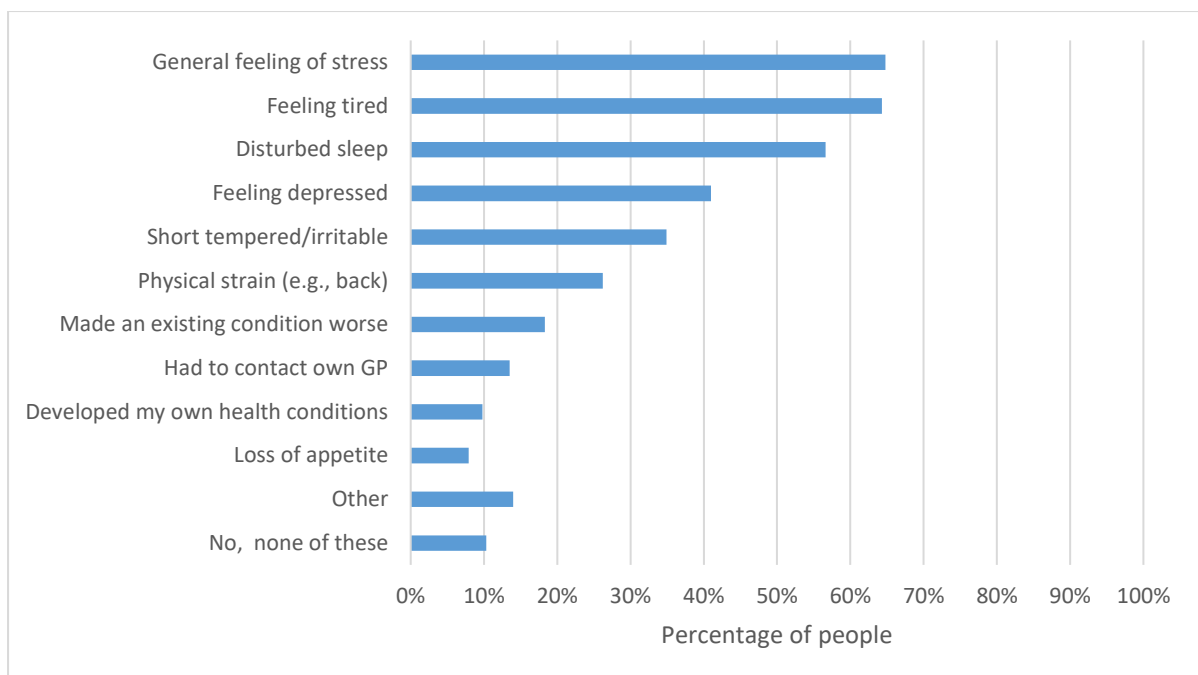


Figure 3.3. In the last four weeks, has your health been affected by your caring role in any of these ways? (Select all that apply)

The most frequently reported ways that carers' health had been affected by their caring role in the last four weeks were reported by over half of carers and support staff in Cohort 2; these were disturbed sleep (57%), feeling tired (64%), or a general feeling of stress (65%). 51 (14%) carers reported having to contact their own GP in the last 4 weeks regarding their health. These results differ from those in the Personal Social Services Survey of Adult Carers in England 2018-19<sup>10</sup>, where this question was also asked. In that survey, the most frequently reported responses in the sample of 10,450 family carers of adults with learning disabilities were that they developed their own health condition (23%) and that they had to see their own GP (22%). The most frequently selected response was 'No, none of these' (26%). The three most frequently reported ways that carers' health had been affected by their caring role in our survey, disturbed sleep, feeling tired, and a general feeling of stress were reported at lower levels in the Personal Social Services Survey of Adult Carers in England 2018-19 (20%, 20%, and 21% respectively).

We also asked participants in Cohort 2 about what would make their lives as a family carer or support worker better. A sample of the comments made are presented in Box 3.1.

<sup>10</sup> <https://digital.nhs.uk/data-and-information/publications/statistical/personal-social-services-survey-of-adult-carers/england-2018-19> (accessed 19th March 2021)

“To be able to give him a cuddle.”

“Clear information and not having to fight for everything, including vaccines - it is exhausting and the same old story that people with learning disabilities are forgotten about, as are their families especially siblings.”

“Getting a proper break from caring 24/7.”

“Getting the vaccination for the person ASAP and the immediate family that care for her every day.”

“To be able to have family come to visit, for my son to go back to day service support as usual. For everything to go back to normal.”

“For us both to be vaccinated. Our lives would change dramatically. I’d stop worrying my son is going to die. We would have a lot more choices available. I’d be able to breathe again. My exit strategy is vaccination and I’m keeping him safe 24/7 until that happens.”

“A support network of other people in the same position as myself.”

“To see him, hug him and be able to give him trips, treats and see him happier.”

“Regular testing for support workers/day activity staff and users.”

Box 3.1. What would make your life as a family carer or support staff better right now?

A common response was that having some respite from caring and working, with many participants indicating that they had not had a proper break, or any “me time” for a very long time, would make life better. Other responses were to have people with learning disabilities and their carers recognised as a priority group for the vaccine, and to receive more support. Many family carers who had been separated from their family member with learning disabilities indicated that the most important thing to make their lives better would be to spend more time and have more physical contact with their loved one.





# **Chapter 4: People with Profound and Multiple Learning Disabilities (PMLD) and the COVID-19 pandemic: Results from the Cohort 2 surveys**



In this part of the report, we provide overall descriptive data for people for whom survey respondents said that the label “Profound and Multiple Learning Disabilities (PMLD)” applies<sup>11</sup> from the Cohort 2 surveys, as well as comparisons between this sub-group and the rest of Cohort 2 where these differences are meaningful.

#### **4.1. Descriptive data about people with PMLD**

In Cohort 2 (n=377), 166 participants were supporting/caring for people with PMLD. Full demographic data about the people with and without PMLD in this cohort are presented in Table 4.1. Detail about who people with and without PMLD live with is presented in Table 4.2.

Table 4.1. Demographic data of people with and without PMLD from the Cohort 2 surveys

	<b>People with PMLD (n = 166)</b>	<b>People without PMLD (n = 211)</b>
<b>Gender</b>		
Male	49%	60%
Female	48%	37%
Other	3%	3%
<b>Age</b>		
16-24	32%	28%
25-34	28%	31%
35-44	16%	18%
45-54	8%	13%
55-64	4%	7%
65+	2%	4%
<b>Ethnicity</b>		
Asian	1%	2%
Black	0%	0%
Mixed ethnic background	5%	1%
White	92%	93%
Other ethnic background	2%	2%
<b>Where they live</b>		
Town	43%	48%
City	34%	28%
Village	24%	25%
<b>Relationship to person cared for</b>		
Family Carer	80%	76%
Support Worker/Paid Carer	13%	14%
Other	7%	10%
<b>Down syndrome</b>	11%	23%

<sup>11</sup> We collected no data to confirm whether the people reported as having PMLD would meet international definitions for PMLD. In the remainder of this report though we refer to those “with” PMLD

Table 4.2. Who people with PMLD live with

	People with PMLD	People without PMLD
<b>Who does the person live with?</b>		
Live with family with no support from staff	34%	45%
Live with other people with learning disabilities with support staff coming into their home	25%	21%
Live with family with support staff coming into their home	25%	13%
Live alone with support staff coming into their home (supported accommodation)	7%	10%
Live alone with no support from staff	2%	2%
Live in a Shared Lives arrangement	3%	1%
Other	5%	10%

Family carers/paid support staff of people with PMLD were 2.4 times less likely to report that the person they support/care for had Down syndrome, compared to people without PMLD ( $p = .01$ ).

## 4.2. COVID-19

In this sub-section, we report the findings from the Cohort 2 surveys about questions that were specific to COVID-19, separated by whether the person completing the survey was caring for someone with or without PMLD. These are:

- whether they had a health condition that made them worry about getting COVID-19,
- whether they had been tested for COVID-19,
- whether they, or anyone they knew, had had COVID-19,
- whether they had been hospitalised because of COVID-19 symptoms,
- whether they were, or had previously been, shielding (whether they had received an official shielding letter or not)
- whether they had self-isolated,
- whether personal protective equipment (PPE) was being worn by their family carers or support staff,
- about wearing face masks/coverings,
- whether they knew someone who had died because of COVID-19, and
- about COVID-19 vaccinations.

### 4.2.1. Health conditions, having COVID-19 and testing for COVID-19

We asked family carers and paid support staff whether the person they support/care for had a health condition that made them worry about the person they support/care for catching COVID-19. The data from each group within Cohort 2 (people with PMLD and people without PMLD) are displayed in Figure 4.1.

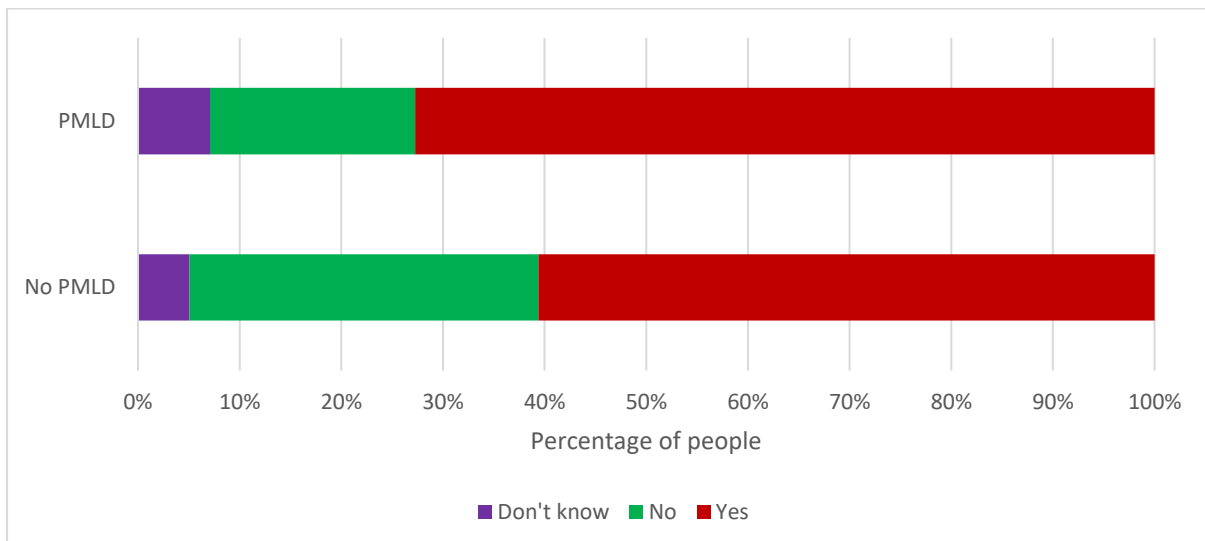


Figure 4.1. Does the person you support/care for have a health condition that makes you worry about them having COVID-19?

Family carers/paid support staff of people with PMLD were 1.8 times more likely to report that the person they support/care for had a health condition that was concerning should they get COVID-19, compared to those without PMLD (72% vs 60%;  $p = .01$ ). The most common health conditions for people with PMLD were:

asthma and epilepsy. For people without PMLD, the most common health condition was also epilepsy.

We also asked participants in Cohort 2 whether people with and without PMLD had been tested for COVID-19. The number of people in both groups who had had a COVID-19 test, and the results of these tests, are displayed in Table 4.3. If there had been more than one COVID-19 test, we asked participants to answer about the most recent one that the person with learning disabilities had had.

Table 4.3. Testing for COVID-19

	<b>People with PMLD (n=67)</b>	<b>People without PMLD (n=69)</b>
<b>Yes – positive result</b>	9%	7%
<b>Yes – negative result</b>	32%	25%
<b>Yes – unclear result</b>	1%	1%
<b>Yes – awaiting result</b>	1%	<1%
<b>No</b>	59%	66%
<b>Don't know</b>	1%	1%

Overall, 43% of people with PMLD and 33% of people without PMLD in Cohort 2 were reported to have had a COVID-19 test. In both groups, of the 67 people with PMLD and the 69 people without PMLD to have a COVID-19 test, the vast majority were negative (78% and 75% respectively).

We also asked family carers and paid support staff in both groups about whether the person they support/care for had had COVID-19. These questions related to the person with learning disabilities themselves, as well as their family members, the people they lived with, and their support workers. We were interested in cases that had been confirmed by a doctor or a test, as well as cases where the person thinks they had COVID-19 but this was not confirmed by a doctor or test. The data for these questions are reported in Figure 4.2, and are separated into the two groups in Cohort 2 (people with PMLD and people without PMLD).

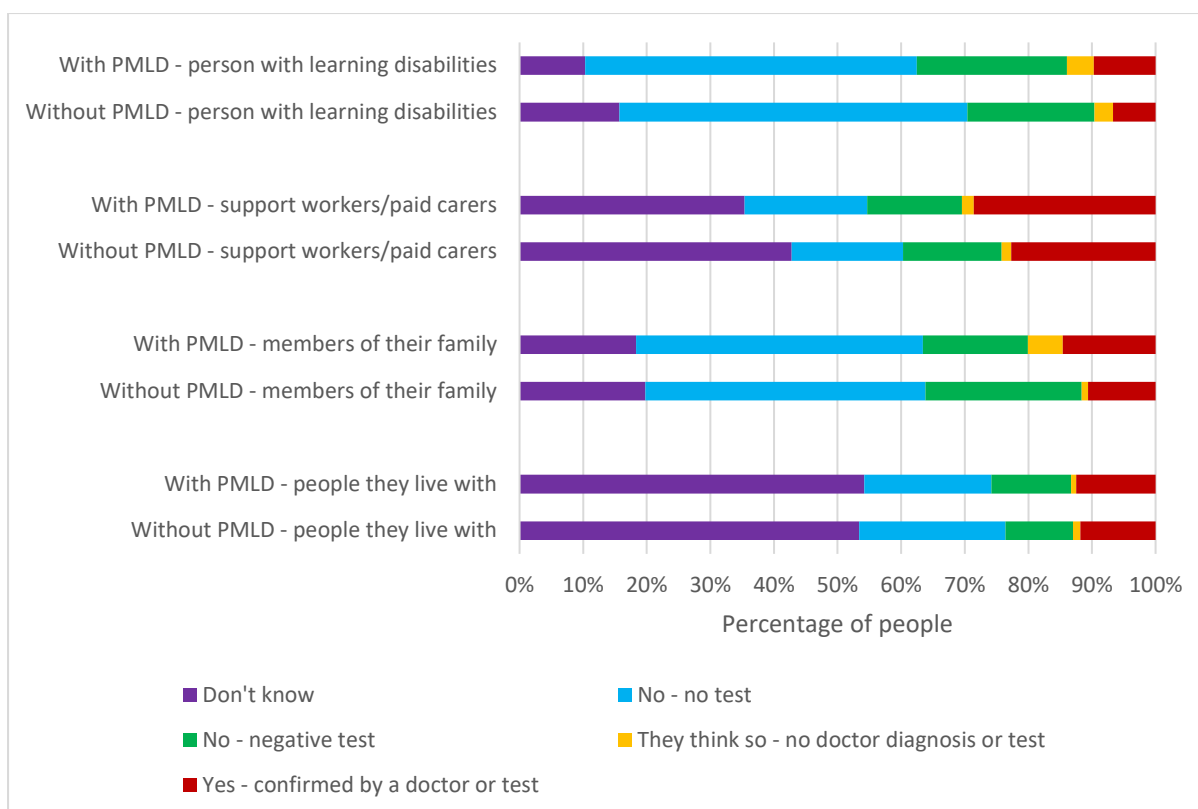


Figure 4.2. Who has had COVID-19

In Cohort 2, 14% of family carers and paid support staff of people with PMLD thought that the person they cared for had had COVID-19, compared to 10% of family carers and paid support staff of people without PMLD.

For the people with PMLD, of the 23 who had a confirmed or suspected case of COVID-19, 4 (17%) were hospitalised because of their COVID-19 symptoms, compared to 2 (10%) of the 20 people without PMLD.

#### 4.2.2. Shielding and self-isolating

We asked family carers/paid support staff who supported/cared for people with and without PMLD about shielding, asking whether people in both groups had ever shielded (Table 4.4) and whether they were shielding at the time of the survey being completed.

Table 4.4. Shielding at all since March 2020, including current shielding

	People with PMLD	People without PMLD
<b>They have shielded since March 2020</b>		
Yes – shielding letter without being requested	23%	23%
Yes – shielding letter after being requested	6%	4%
Yes – self-imposed “shielding”	34%	26%
No	36%	43%
Don't know	2%	3%

Of the 103 people with PMLD and 112 people without PMLD who had ever shielded since March 2020, 63% of people with PMLD and 53% of people without PMLD were shielding when their family carer/paid support staff member completed their survey.

We also asked carers of people with and without PMLD about self-isolation in the last four weeks because the person they support/care for had COVID-19 symptoms or had been in close contact with someone who had COVID-19. The percentages of people with learning disabilities in both groups who self-isolated in the last four weeks are displayed in Figure 4.3.

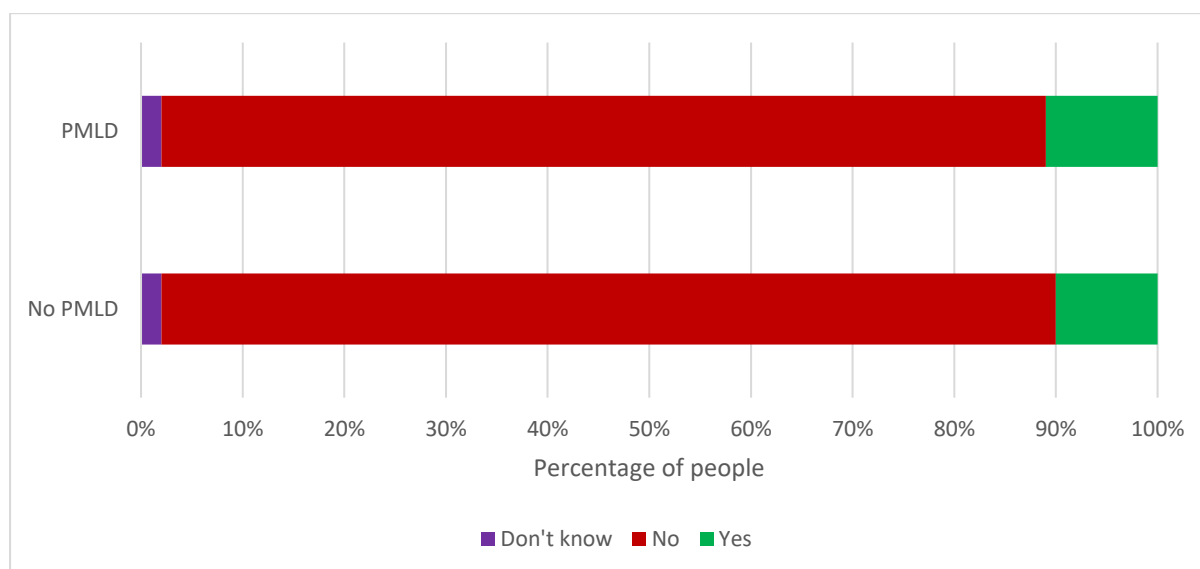


Figure 4.3. Person with learning disabilities self-isolated because of COVID-19 symptoms or close contact with someone who had COVID-19 symptoms

The vast majority of people with learning disabilities in both groups had not self-isolated.

#### 4.2.3. Personal protective equipment (PPE) and face masks/coverings

We asked family carers/paid support staff of people with and without PMLD about whether the person with learning disabilities' family carers/paid support staff wore PPE. We also asked about whether they had had any difficulties in accessing PPE, and whether them wearing PPE had had an impact on the relationship between the family carer/paid support staff participant and the person with learning disabilities. These data are presented in Table 4.5.

Table 4.5. Family carer/paid support staff use of PPE

	People with PMLD	People without PMLD
<b>Family carers/paid support staff wear PPE</b>		
Yes	59%	40%
No	41%	59%
Don't know	1%	1%
<b>Difficulties in family carer/paid support staff accessing PPE</b>		
Yes – difficulties in the past, okay now	29%	22%
Yes – still have difficulties	8%	7%
No	60%	65%
Don't know	4%	6%
<b>Impact of carer PPE on relationship of the family carer/paid support staff and person with learning disabilities</b>		
Negative impact	25%	30%
Not much difference	74%	69%
Positive impact	1%	1%

Family carers/paid support staff of people with PMLD were 2.1 times more likely to wear PPE, compared to family carers/paid support staff of people without PMLD ( $p = .01$ ). Of the 96 and 82 family carers/paid support staff of people with and without PMLD respectively who wore PPE when caring for people with learning disabilities, as many as 37% (family carers/paid support staff of people with PMLD) of them had found it difficult to access PPE, either in the past or at present. Over two-thirds of family carers and paid support staff in both groups (74% for family carers/paid support staff of people with PMLD and 69% of family carers/paid support staff of people without PMLD) reported that wearing PPE had not made much difference to their relationship with the person they support/care for.

We also asked whether people with learning disabilities were wearing face masks/coverings when they were going out, and what their experiences of wearing these were. These data are presented in Table 4.6.

Table 4.6. Use of face masks/coverings by people with learning disabilities

	People with PMLD	People without PMLD
<b>Worn a face mask/covering in last 4 weeks</b>		
Yes	36%	72%
No	41%	16%
Don't know	3%	2%
Not been out in last 4 weeks	20%	10%
<b>Exempt from wearing face mask/covering</b>		
Yes	70%	38%
No	16%	45%
Don't know	14%	18%
<b>Reasons for not wearing face mask/covering</b>		
Does not understand why they have to wear one	42%	27%
They find it uncomfortable to wear	14%	14%
They make it hard for them to communicate	10%	10%
They make it difficult to breathe	9%	9%
They might have a seizure	9%	4%
They get a skin irritation from them	3%	1%
Other	10%	9%

People with PMLD were reported to be 5.1 times less likely to wear a face mask/covering, compared to people without PMLD ( $p < .001$ ). People with PMLD were also reported to be 3.9 times more likely to be exempt from wearing a face mask/covering ( $p < .001$ ). For those exempt from wearing a face mask/covering, 42% of the 166 people with PMLD were reported to not understand the reasons why they had to wear one, compared to 27% of the 79 people without PMLD.

#### 4.2.4. Deaths from COVID-19

One of the particularly pressing COVID-19-specific questions for people with learning disabilities identified by our advisory groups was how many people knew someone who had died from COVID-19. These data are displayed for people with and without PMLD in Cohort 2, in Figure 4.4.



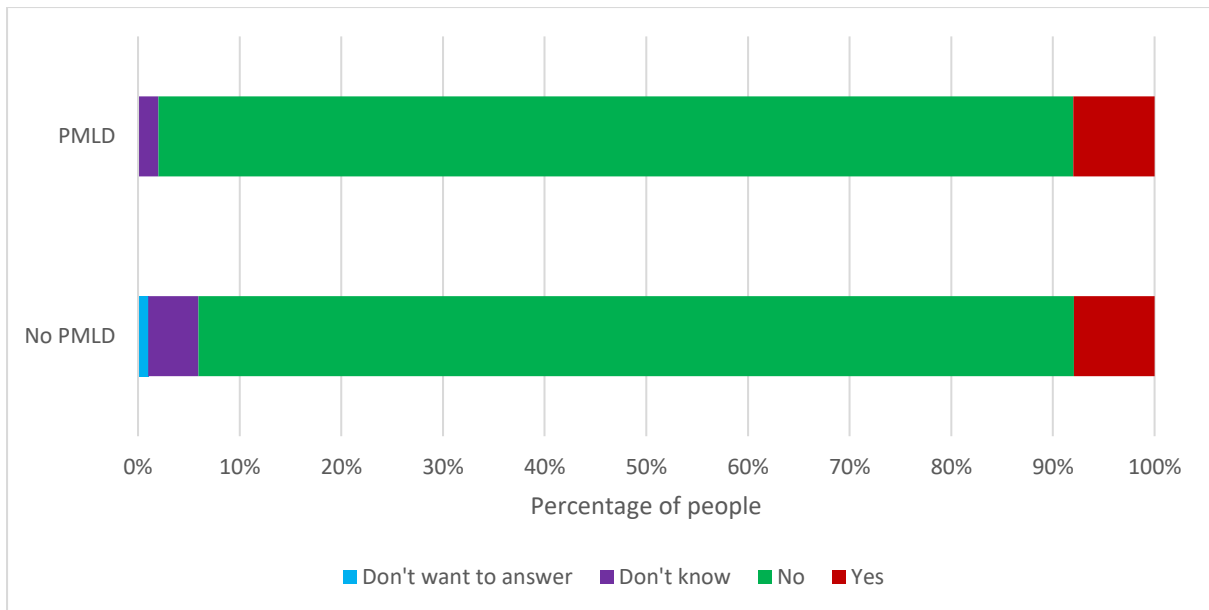


Figure 4.4. Has anyone close to the person you support/care for died from COVID-19? This could be a family member and friend, a person they were sharing a house with or a person who supported them.

A similar proportion of people with PMLD and people without PMLD have experienced someone close to them die from COVID-19 (7.9% and 7.6% respectively).

#### 4.2.5. COVID-19 vaccinations

Another pressing question for people with learning disabilities in our advisory groups at the time of deciding questions for Wave 1 was how many people with learning disabilities would take a COVID-19 vaccine if they were offered it. These data are displayed for people with and without PMLD in Cohort 2, in Figure 4.5.

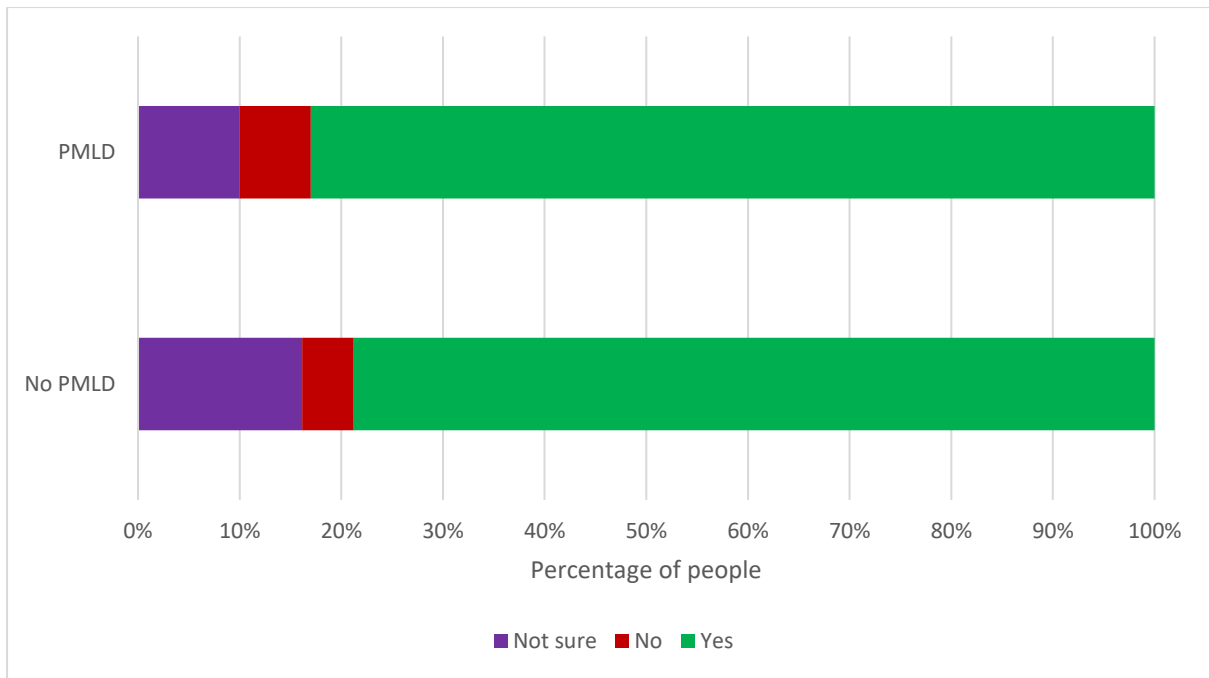


Figure 4.5. If the person you support/care for was offered a coronavirus vaccine would they have it?

The vast majority of family carers/paid support staff in Cohort 2 indicated that people with and without PMLD (83% and 78% respectively) indicated that they would take the COVID-19 vaccine if it were offered to them.

### **4.3. Physical health and access to health services**

In this sub-section, we report the findings from the Cohort 2 surveys about the physical health of people with learning disabilities and their access to health services during the COVID-19 pandemic, separated by whether the person completing the survey was caring for someone with or without PMLD. These are:

- the current health of people with learning disabilities, with and without PMLD
- what has happened to the existing health services that they used regularly before March 2020,
- what has happened to planned medical tests, appointments and operations, and
- what is happening with preventative health measures (e.g., annual health check, flu vaccination).

#### **4.3.1. Current health of people with learning disabilities, with and without PMLD**

When asked about their general health today, family carers/paid support staff of people with PMLD most commonly rated the health of the person they support/care for as good (60%). Family carers/paid support staff of people without PMLD reported the health of the person they support/care for as good (56%).

For people with and without PMLD, most family carers/paid support staff said that the health of the person they support/care for had stayed about the same since the start of the first national lockdown in March 2020 (63% and 64% respectively). However, almost a third of family carers/paid support staff of people with and without PMLD (33% and 28% respectively) said the person with learning disabilities' health had changed for the worse. All data for these questions are displayed in Table 4.7.

Table 4.7. The current health status of people with learning disabilities

	<b>People with PMLD</b>	<b>People without PMLD</b>
<b>Health today</b>		
Good	60%	56%
Ok	33%	34%
Not good	6%	8%
Don't know	1%	2%
<b>Has physical health changed since the first lockdown in March 2020</b>		
Worse	33%	28%
About the Same	63%	64%
Better	4%	9%

We also asked family carers/paid support staff whether they had experienced difficulties in getting essential equipment and resources, and these data are presented in Figure 4.6.

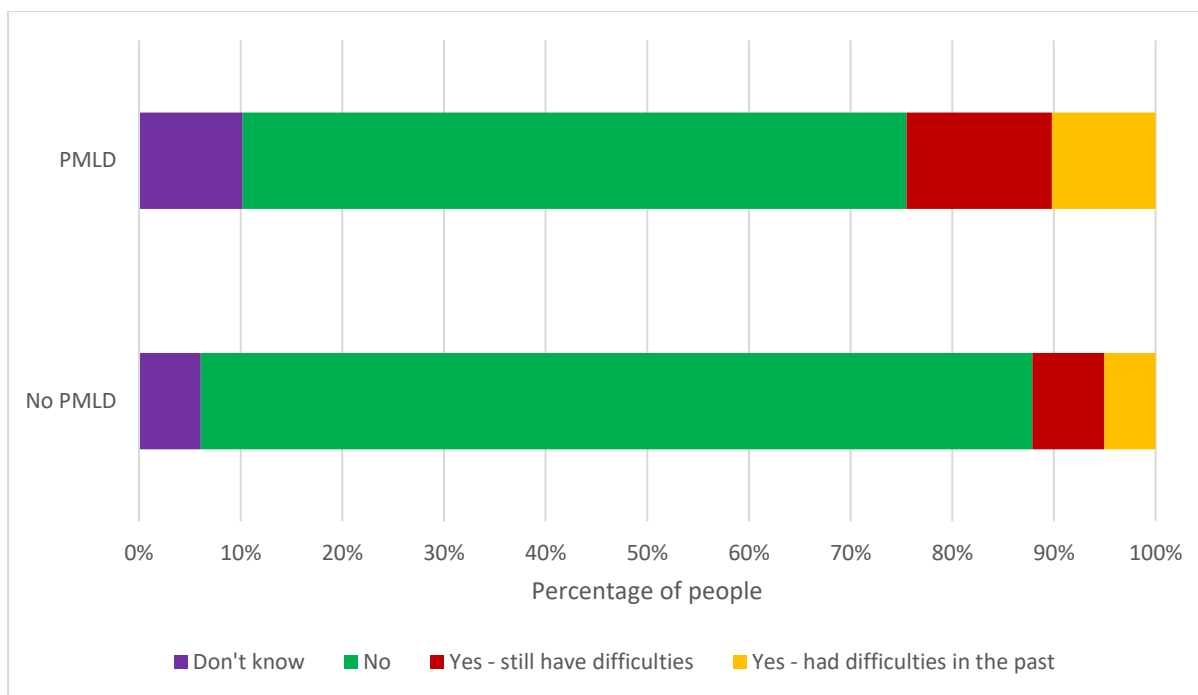


Figure 4.6. Have there been difficulties getting and keeping essential equipment and resources for the person you support/care for?

Family carers/paid support staff of people with PMLD were 2.5 times more likely to have experienced some difficulty in accessing equipment and resources, compared to those who support/care for people without PMLD ( $p < .001$ ). Of the 37 family carers/paid support staff of people with PMLD and the 24 family carers/paid support staff of people without PMLD who reported that they had difficulties in getting and keeping essential equipment for the person they support/care for at some point in time, 57% and 58% respectively were still having difficulties at the time of reporting.

#### 4.3.2. Existing health services for people with learning disabilities

Generally, people with learning disabilities who saw their healthcare professionals regularly before the first lockdown in March 2020 reported seeing them less since the first lockdown. Of all the people with and without PMLD, Table 4.8 reports how many were regularly seeing different healthcare professionals before March 2020.

Table 4.8. People with learning disabilities who saw each healthcare professional regularly before the March 2020 lockdown

	People with PMLD	People without PMLD
<b>GP</b>	50%	42%
<b>Community nurse</b>	38%	27%
<b>Psychiatrist/clinical psychologist/counsellor</b>	24%	30%
<b>Other therapist</b>	50%	27%

The following figures (Figures 4.7-4.10) present data about whether the percentage of people with and without PMLD who saw each healthcare professional regularly before the March 2020 lockdown had seen them since the start of that first lockdown.

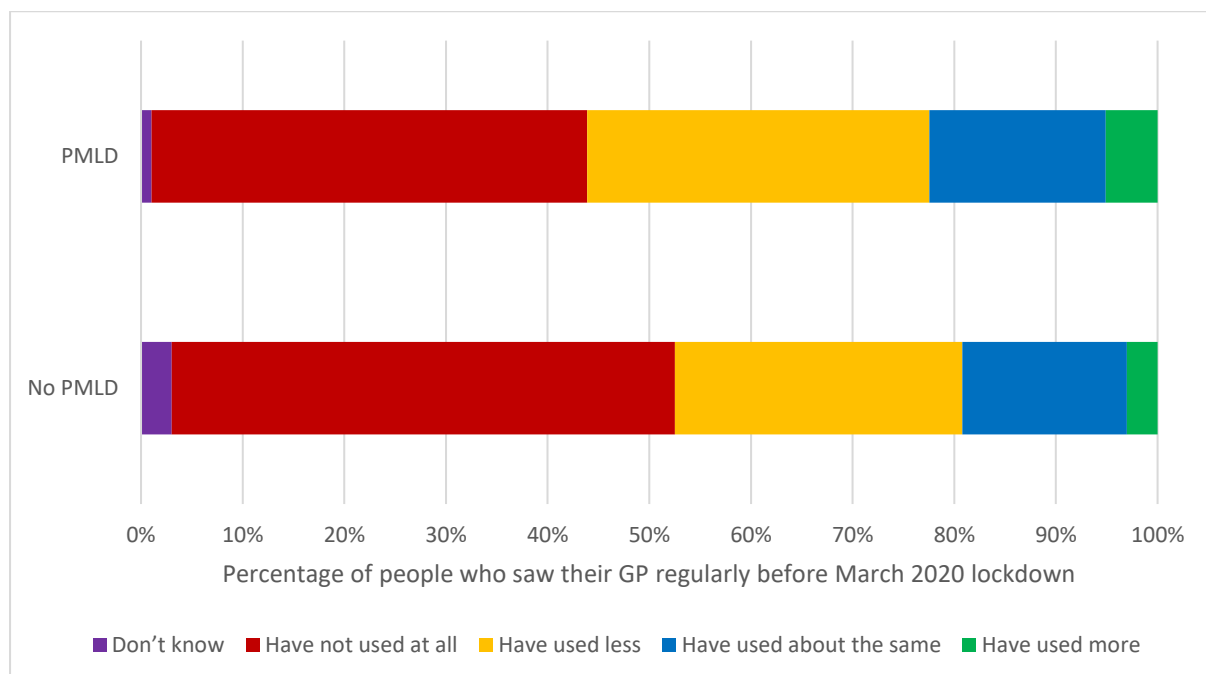


Figure 4.7. The percentage of people with learning disabilities who have seen their GP as much as before the March 2020 lockdown (Sample: People with PMLD (n=82), People without PMLD (n=88))

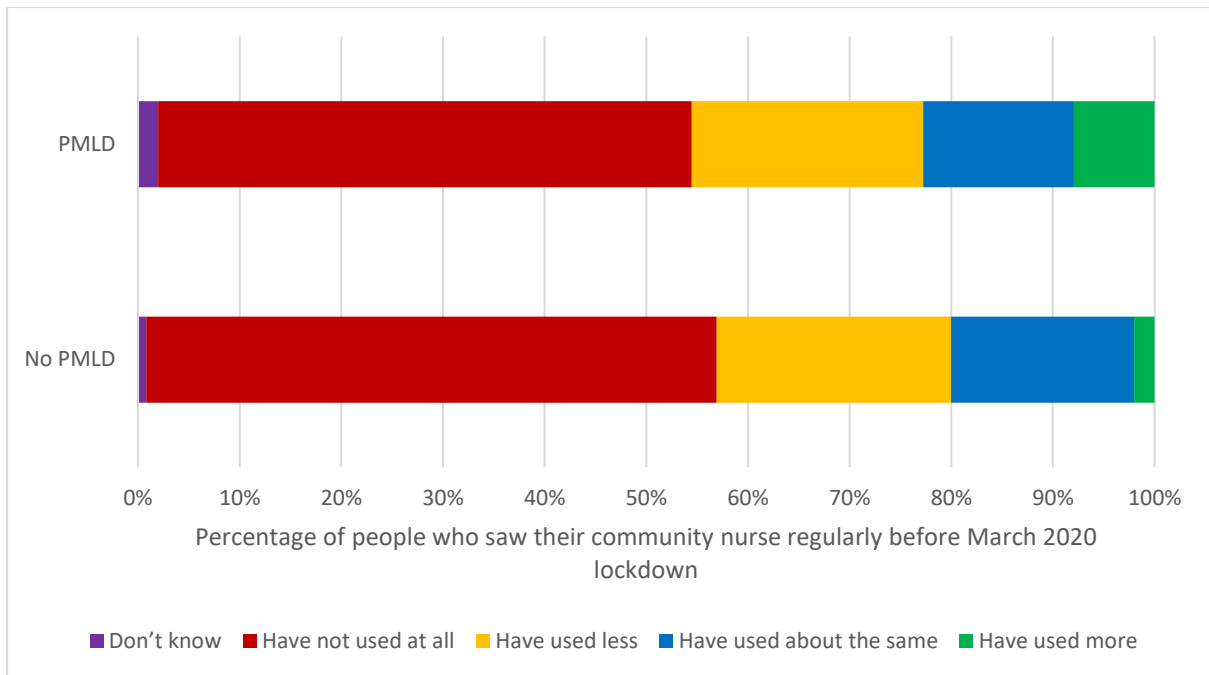


Figure 4.8. The percentage of people with learning disabilities who have seen their community nurse as much as before the March 2020 lockdown (Sample: People with PMLD (n=61), People without PMLD (n=57))

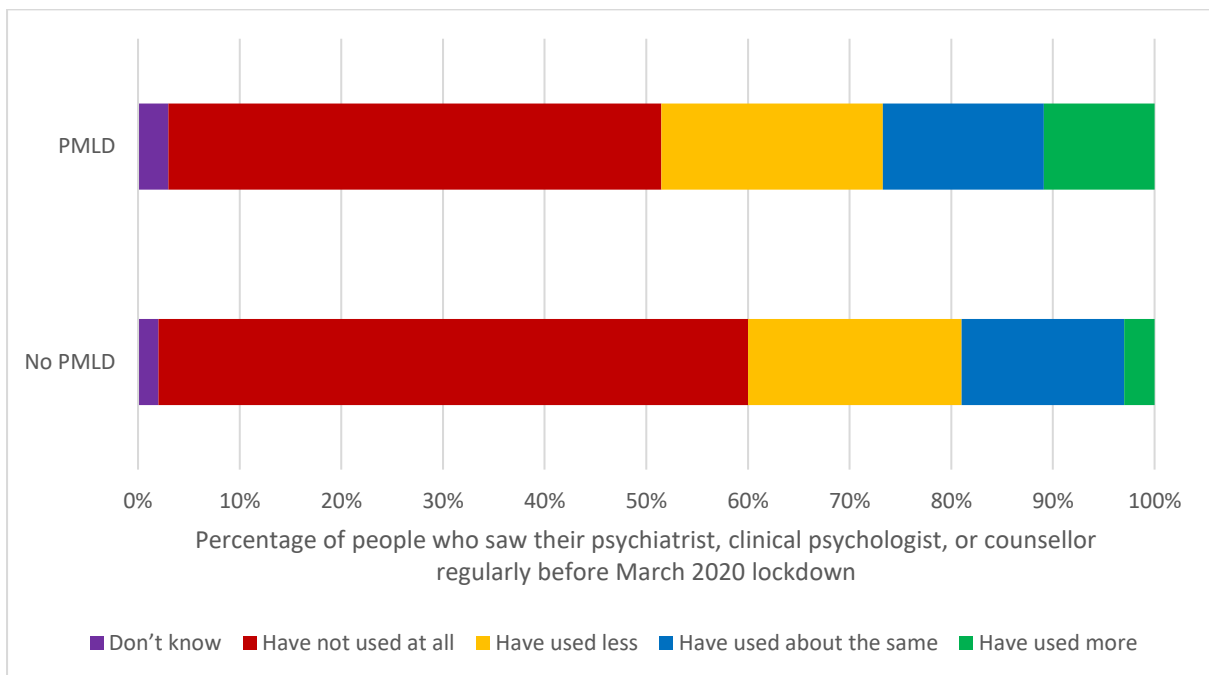


Figure 4.9. The percentage of people with learning disabilities who have seen their psychiatrist, clinical psychologist or counsellor as much as before the March 2020 lockdown (Sample: People with PMLD (n=38), People without PMLD (n=63))

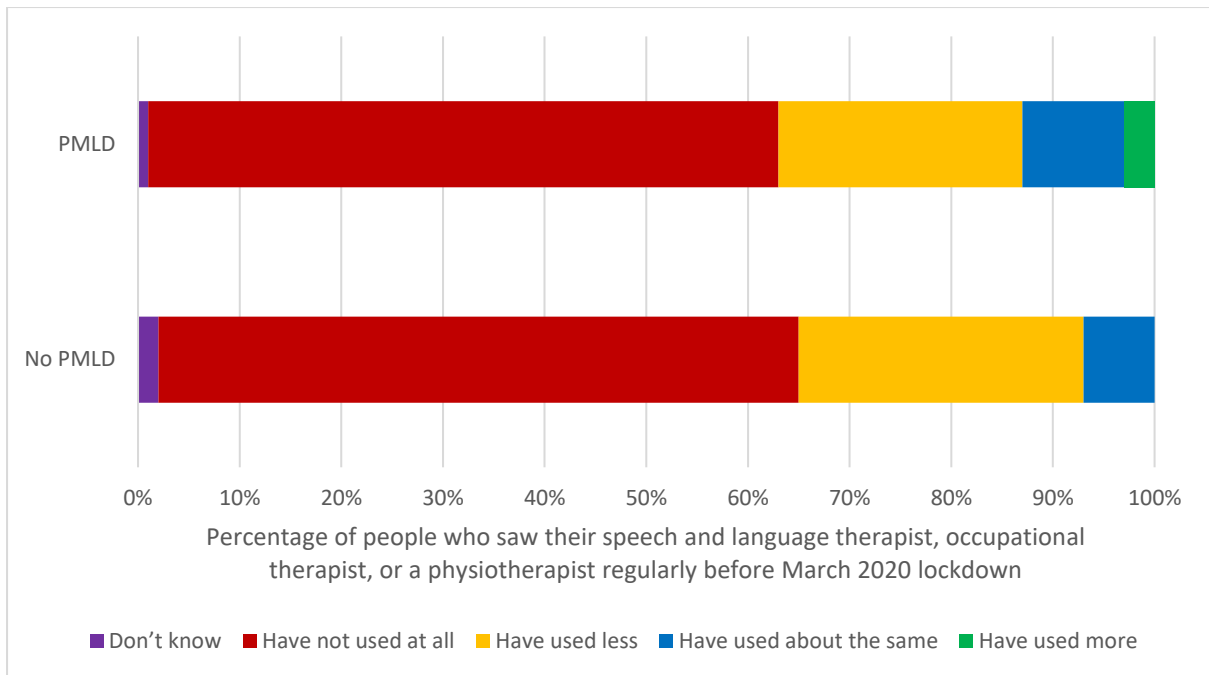


Figure 4.10. The percentage of people with learning disabilities who have seen their speech and language therapist, occupational therapist, or physiotherapist as much as before the March 2020 lockdown (Sample: People with PMLD (n= 79), People without PMLD (n= 55))

In all four instances, and in both cohorts, over 70% of people with and without PMLD who had routinely seen these healthcare professionals before the first lockdown in March 2020, had seen them less or not at all since then.

### 4.3.3. Planned medical tests, appointments, and operations

We also asked about what had happened to planned medical tests, outpatient hospital appointments, and operations for people with and without PMLD in Cohort 2 since the first lockdown in March 2020. These data are presented in Table 4.9 for both cohorts.

Table 4.9. People with learning disabilities who had planned medical tests, operations or appointments been cancelled since the March 2020 lockdown

	People with PMLD	People without PMLD
<b>Planned medical test cancelled</b>		
Yes	28%	29%
No	64%	65%
Don't know	8%	6%
<b>Planned medical operation cancelled</b>		
Yes	6%	5%
No	92%	92%
Don't know	3%	3%
<b>Planned hospital appointment cancelled</b>		
Yes	43%	39%
No	50%	54%
Don't know	7%	6%

Over one-fifth of people with and without PMLD had a medical test or a hospital appointment cancelled since the first lockdown, with as many as 43% of people without PMLD having had a planned hospital appointment cancelled; a number similar to those in people without PMLD (39%).

### 4.3.4. Preventative health measures

Adults with learning disabilities are eligible to have an annual health check with their GP to check and talk about their general health and to spot the early signs of health conditions (e.g., diabetes). They can help people with learning disabilities to get to know their GP better, which can help them to feel more comfortable contacting them if they do get ill. Further information about annual health checks is presented in Figure 4.11 for people with and without PMLD.



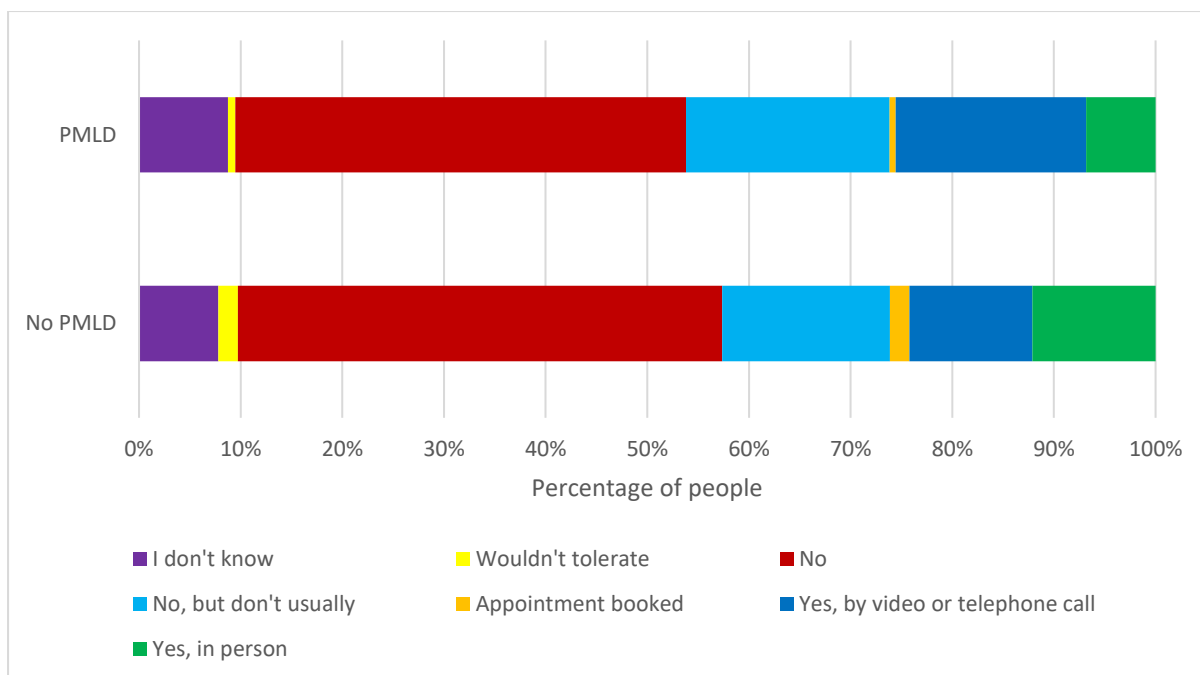


Figure 4.11. Since the start of the first lockdown in March 2020, has the person you support/care for had their annual health check?

For both groups of people with and without PMLD, 66% have not had an annual health check since the first national lockdown in March 2020.

Adults with learning disabilities are eligible for a free flu vaccine. The data for the question about flu vaccines for participants in Cohort 2 are reported in Table 4.10.

Table 4.10. Has the person you support/care for had a flu vaccine (flu jab or nasal spray) for this flu season (winter 2020/2021)?

	People with PMLD	People without PMLD
<b>Flu vaccine</b>		
Yes	72%	68%
No	17%	5%
Don't want a flu vaccine	1%	17%
Would not tolerate a flu vaccination	6%	6%
Don't know	4%	4%

The majority of people with and without PMLD had had their Winter 2020/21 flu vaccine (72% and 68% respectively).

#### 4.4. Wellbeing and mental health

We also asked some general questions about the wellbeing of people with learning disabilities, both with and without PMLD, since the start of the first national lockdown in March 2020, and these data are presented in Figure 4.12.

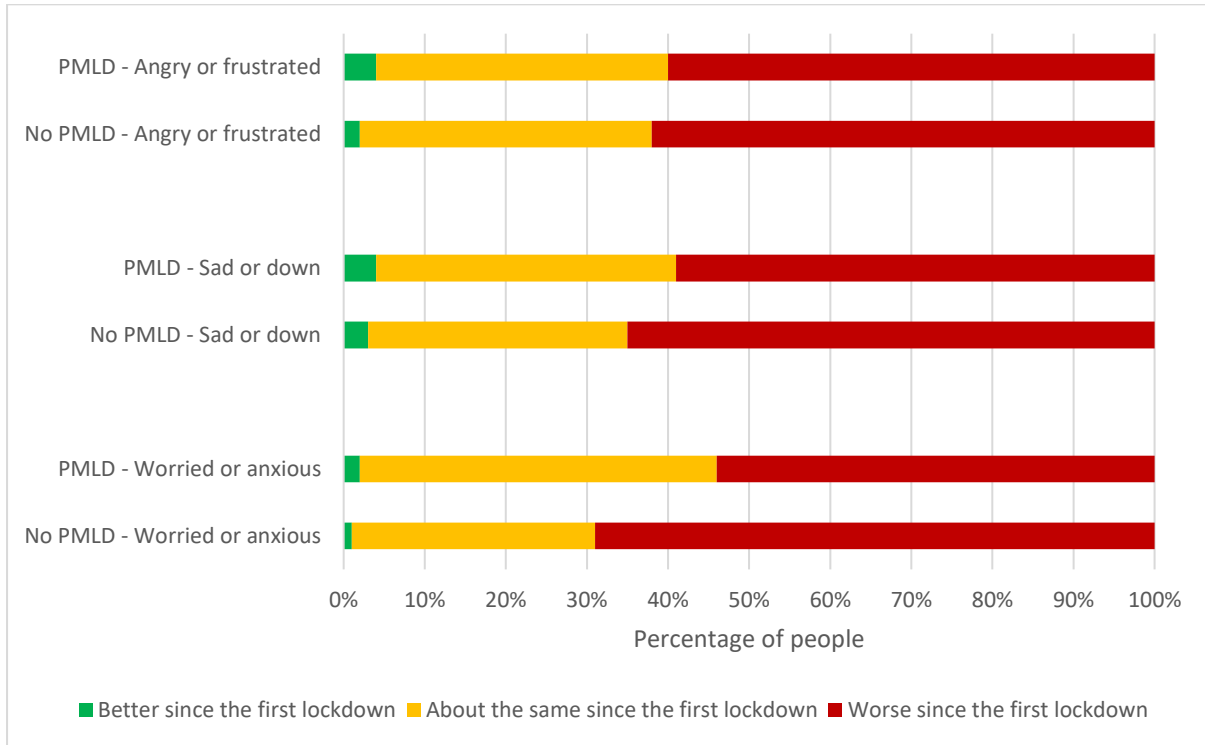


Figure 4.12. How people with learning disabilities have felt compared to before the start of the first lockdown in March 2020

Most family carers/paid support staff of people with and without PMLD reported that the well-being of the person they support/care for had been worse since the first lockdown in March 2020 across all three questions. These percentages were marginally higher for people without PMLD, compared to people with PMLD, on all three questions.

## **4.5. Relationships, social lives, and digital inclusion**

In this sub-section, we report the findings from the Cohort 2 surveys about the relationships, social lives, and digital inclusion of people with learning disabilities during the COVID-19 pandemic, separated by whether the person completing the survey was caring for someone with or without PMLD. These are:

- how they are staying in touch with their family and friends,
- how they are getting on with the people they live with,
- about visitor restrictions where they live, and
- how people are using technology during the COVID-19 pandemic (digital inclusion).

### **4.5.1. Staying in touch with family and friends**

We were interested in understanding the ways in which people with and without PMLD had been staying in contact with others. The most common ways in which family carers and paid support staff described people with learning disabilities staying in touch with other people are presented in Table 4.11.

Table 4.11. How people with learning disabilities stay in contact with friends, family and other people

	People with PMLD	People without PMLD
<b>Face-to-face</b>		
Do this now	19%	25%
Did prior to lockdown	70%	76%
Never did this nor do they now	14%	9%
<b>Meet outside</b>		
Do this now	19%	21%
Did prior to lockdown	74%	78%
Never did this nor do they now	10%	14%
<b>Meet in others' house</b>		
Do this now	4%	9%
Did prior to lockdown	67%	76%
Never did this nor do they now	25%	20%
<b>Meet in own house</b>		
Do this now	7%	10%
Did prior to lockdown	76%	80%
Never did this nor do they now	14%	15%
<b>Meet in other indoor places</b>		
Do this now	8%	12%
Did prior to lockdown	82%	82%
Never did this nor do they now	11%	10%
<b>Talk on telephone</b>		
Do this now	30%	62%
Did prior to lockdown	15%	36%
Never did this nor do they now	60%	27%
<b>Through video calls</b>		
Do this now	58%	66%
Did prior to lockdown	11%	18%
Never did this nor do they now	36%	27%

Video calling and talking on the telephone increased post-lockdown for both people with PMLD (47% increase and 15% increase) and people without PMLD (48% increase and 36% increase).

#### 4.5.2. Relationships with the people they live with

We also asked questions about how people with and without PMLD were getting on with the people they lived with. Figure 4.13 presents the data from these questions broken down by people who live with their family and people who live with other people with learning disabilities.

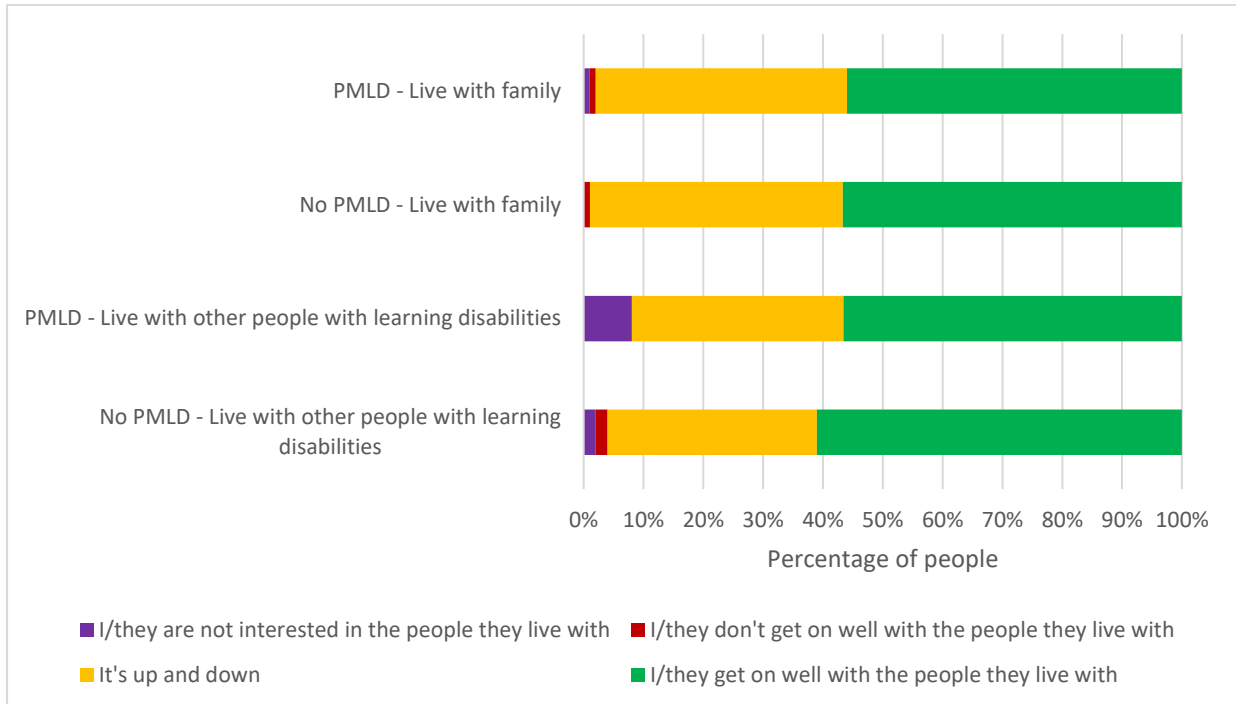


Figure 4.13. In the last four weeks, how has the person you support/care for got on with the people they live with?

In both groups of people with and without PMLD, people with learning disabilities generally got on well with the people they lived with (>50% in all four instances), regardless of whether they lived with their family or other people with learning disabilities.

#### 4.5.3. Visitor restrictions

We asked family carers/paid support staff of people with and without PMLD some questions about visitor restrictions, including the extent of restrictions for family and friends, and for professionals. These data are presented in Table 4.12.

Table 4.12. Visitor restrictions for people with learning disabilities since the first lockdown in March 2020

	People with PMLD	People without PMLD
<b>Are they allowed access/visits from families and friends</b>		
Full access	4%	5%
Restrictions on some occasions	15%	22%
Partial access	36%	35%
Only Key Worker family and friends	23%	15%
No access	19%	21%
Don't know	3%	3%
<b>Restrictions on visits from professionals</b>		
Full access	16%	16%
Restrictions on some occasions	20%	17%
Partial access	32%	29%
No access	27%	28%
Don't know	6%	9%

Around one fifth of people with PMLD and without PMLD had not been allowed any visits from families and friends (19% and 21% respectively) and professionals (27% and 28% respectively) since the start of the first lockdown in March 2020.

We also asked about the impact that these restrictions had had on the people with and without PMLD who were being supported/cared for by participants in Cohort 2. These data are presented in Figure 4.14.

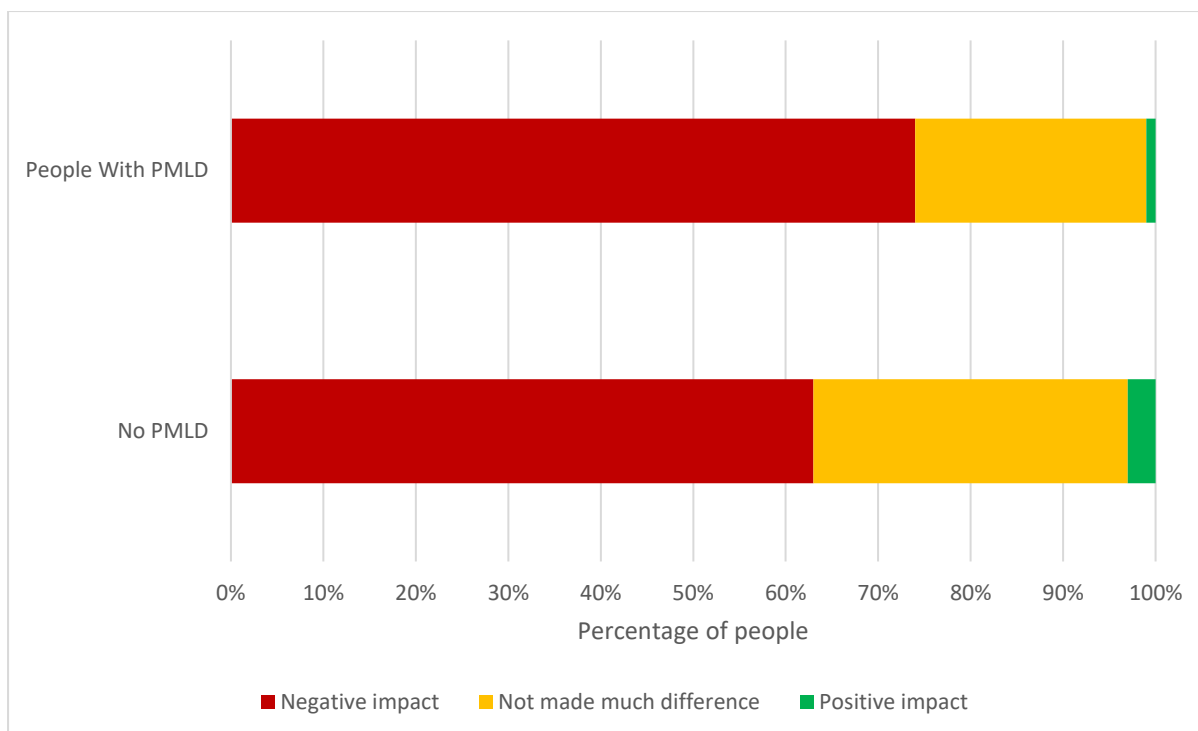


Figure 4.14. Have these restrictions on access/visits had an impact on the person you support/care for?

The majority of people with learning disabilities, with and without PMLD, were reported to have experienced a negative impact as a result of visitor restrictions, and this was particularly the case for people with PMLD (74%) compared to people without PMLD (63%).

#### 4.5.4. Digital inclusion

With a move away from being able to see people, friends, family, and professionals face-to-face, we were interested to know what the digital inclusion of people with learning disabilities was like. In Cohort 2, we were particularly interested in knowing whether people with and without PMLD had access to the internet and a telephone from which to make calls. These data are presented in Table 4.13 below.

Table 4.13. Internet and telephone access and use for people with learning disabilities

	People with PMLD	People without PMLD
<b>Access to internet/telephone</b>		
Internet at home	57%	74%
Device to use internet	46%	66%
Telephone for calls	21%	49%
Internet/phone to be used on their behalf	69%	56%

People with PMLD had generally lower levels of internet access (57%), availability of an internet-ready device (46%), and a telephone for calls (21%) than people without PMLD, but were more likely to have the internet/phone used on their behalf (69%).

## **4.6. Sources of support**

In this sub-section, we report on questions about formal sources of support that people with and without PMLD had access to before and after the first lockdown in March 2020.

Of all the people with and without PMLD who were reported about in Cohort 2, Table 4.14 reports how many were regularly receiving different formal supports before the first lockdown in March 2020.

Table 4.14. The percentage of people with learning disabilities who used different formal supports regularly before the March 2020 lockdown

	<b>People with PMLD</b>	<b>People without PMLD</b>
<b>Day services</b>	68%	53%
<b>Community activities</b>	79%	87%
<b>Further education</b>	18%	26%
<b>Going out with Personal Assistants/Support Workers</b>	72%	53%
<b>Respite/Short breaks away from home</b>	45%	33%
<b>Personal Assistants /Support Workers helping them at home</b>	72%	74%
<b>Social Worker visits</b>	42%	34%
<b>Professional contact by telephone/video call</b>	23%	16%
<b>Support from volunteers</b>	8%	11%

The following figures (Figures 4.15-4.23) present data about whether the percentage of people with learning disabilities, both with and without PMLD, who received the formal support listed in Table 4.14 regularly before the March 2020 lockdown had received them since.



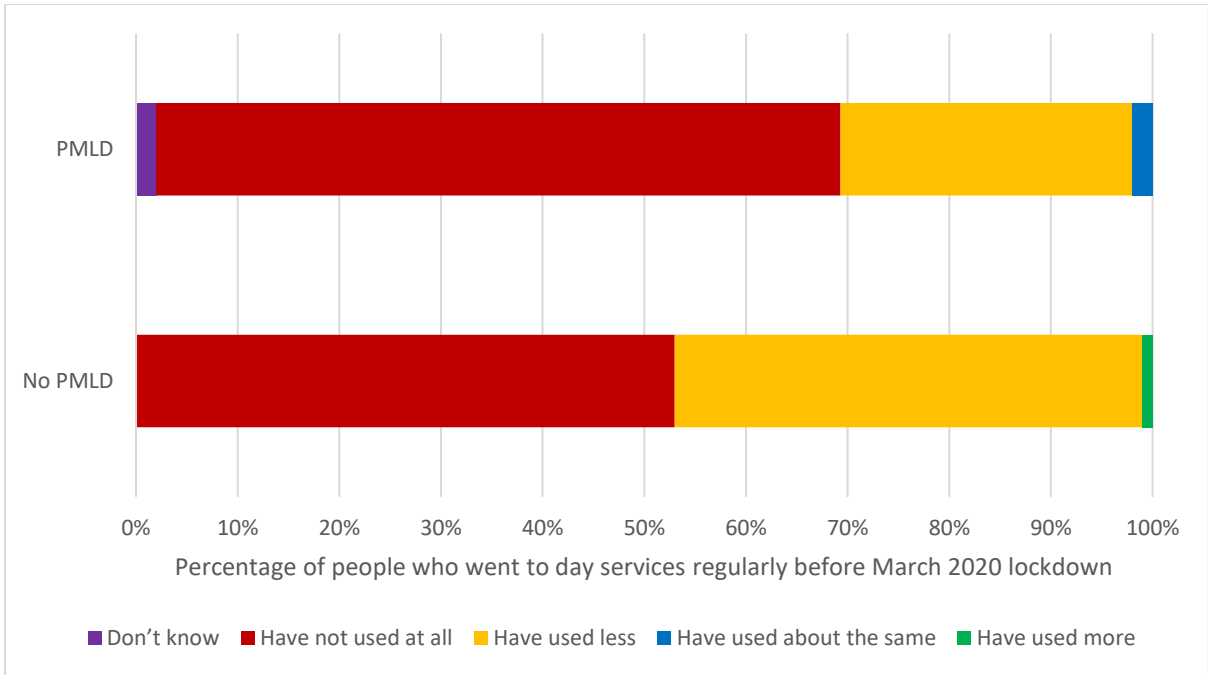


Figure 4.15. The percentage of people with learning disabilities who have gone to day services as much as before the March 2020 lockdown (Sample: People with PMLD (n=108), People without PMLD (n=107))

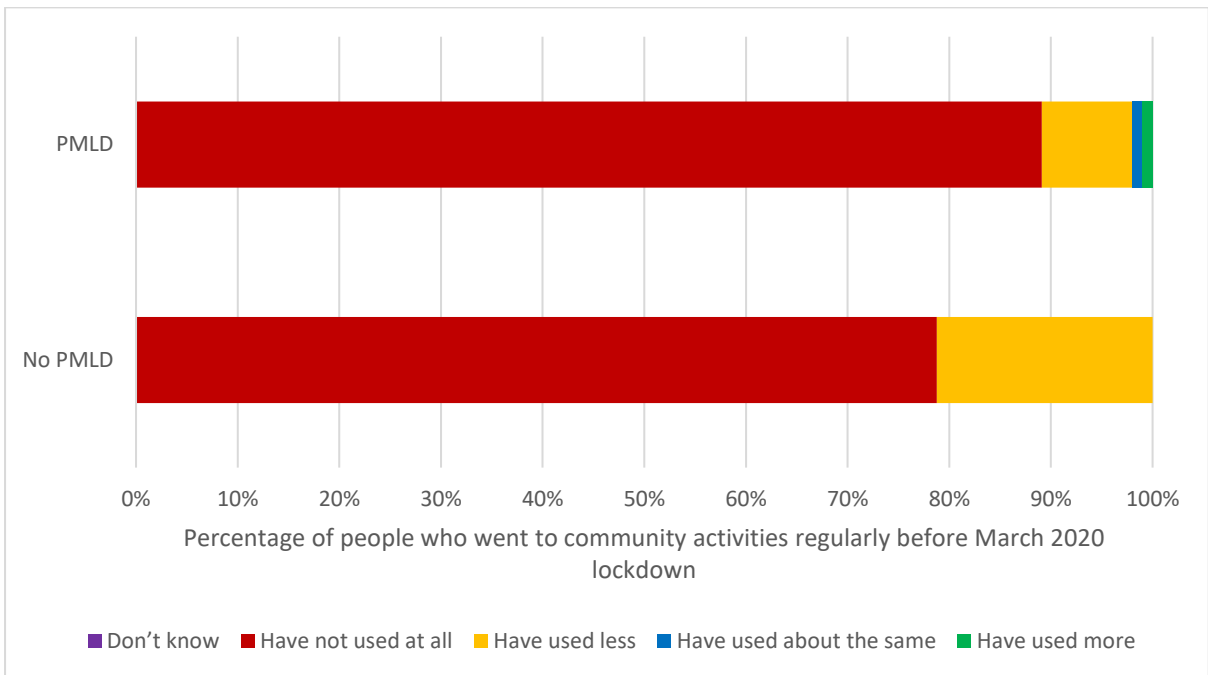


Figure 4.16. The percentage of people with learning disabilities who have gone to community activities as much as before the March 2020 lockdown (Sample: People with PMLD (n=126), People without PMLD (n=176))

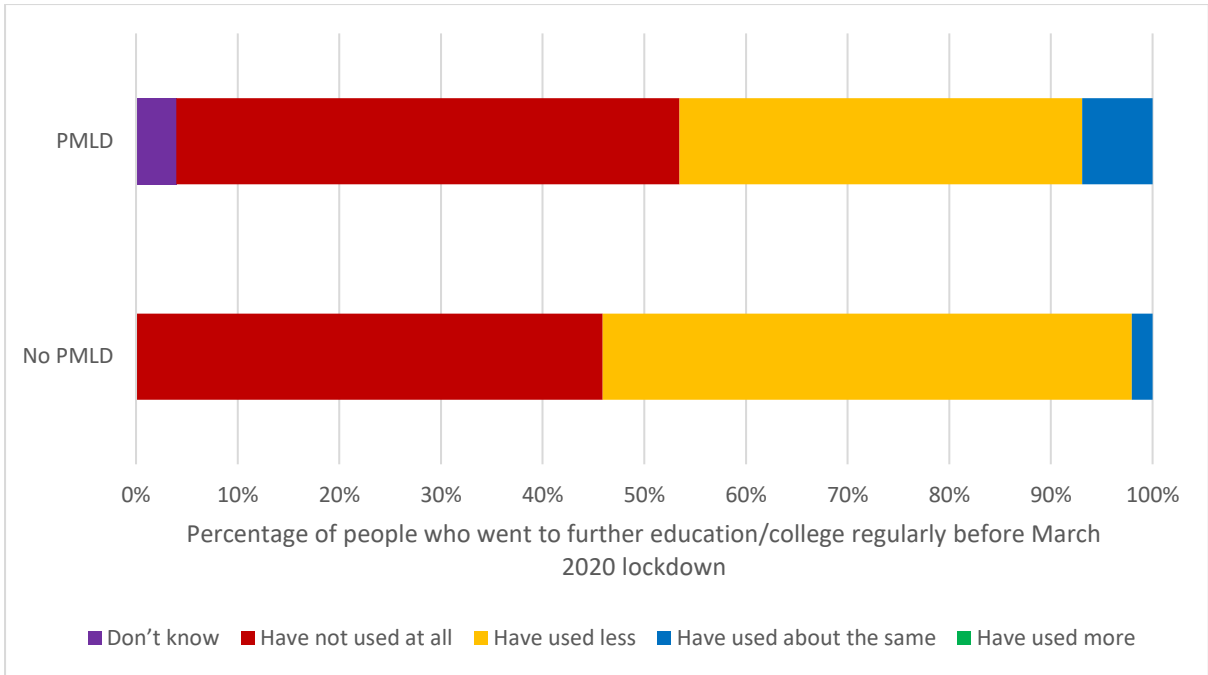


Figure 4.17. The percentage of people with learning disabilities who have gone to further education/college as much as before the March 2020 lockdown (Sample: People with PMLD (n=28), People without PMLD (n=53))

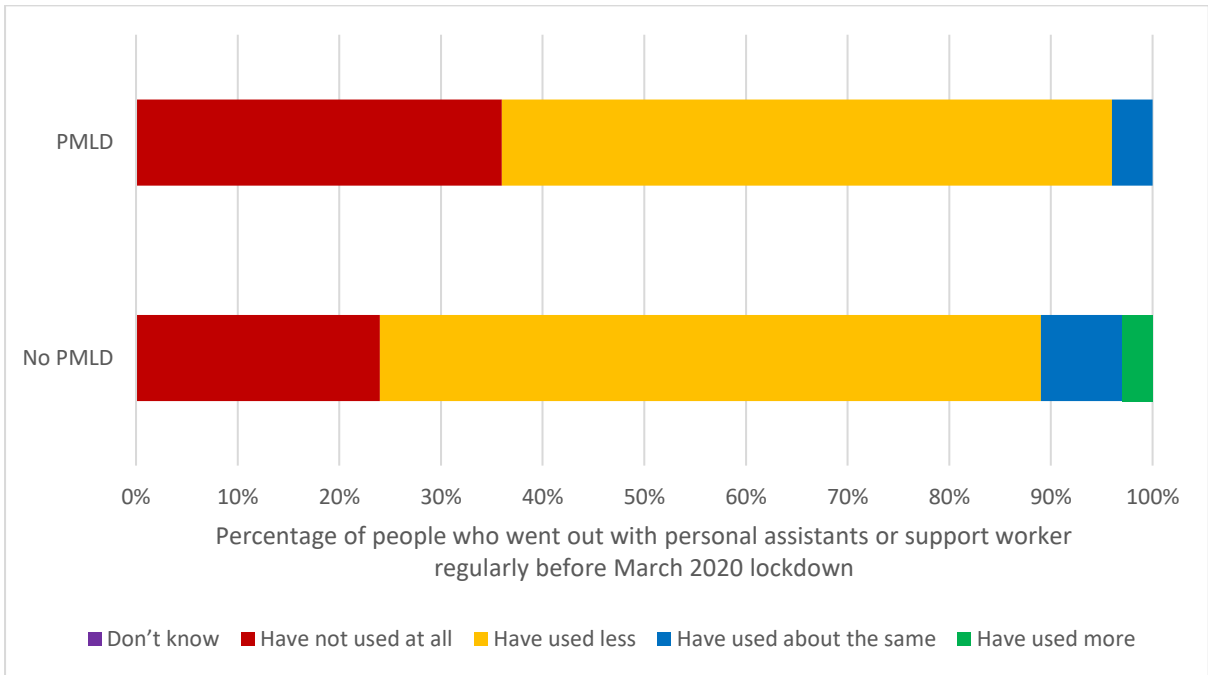


Figure 4.18. The percentage of people with learning disabilities who have gone out of the house with a personal assistant or support worker as much as before the March 2020 lockdown (Sample: People with PMLD (n=124), People without PMLD (n=148))

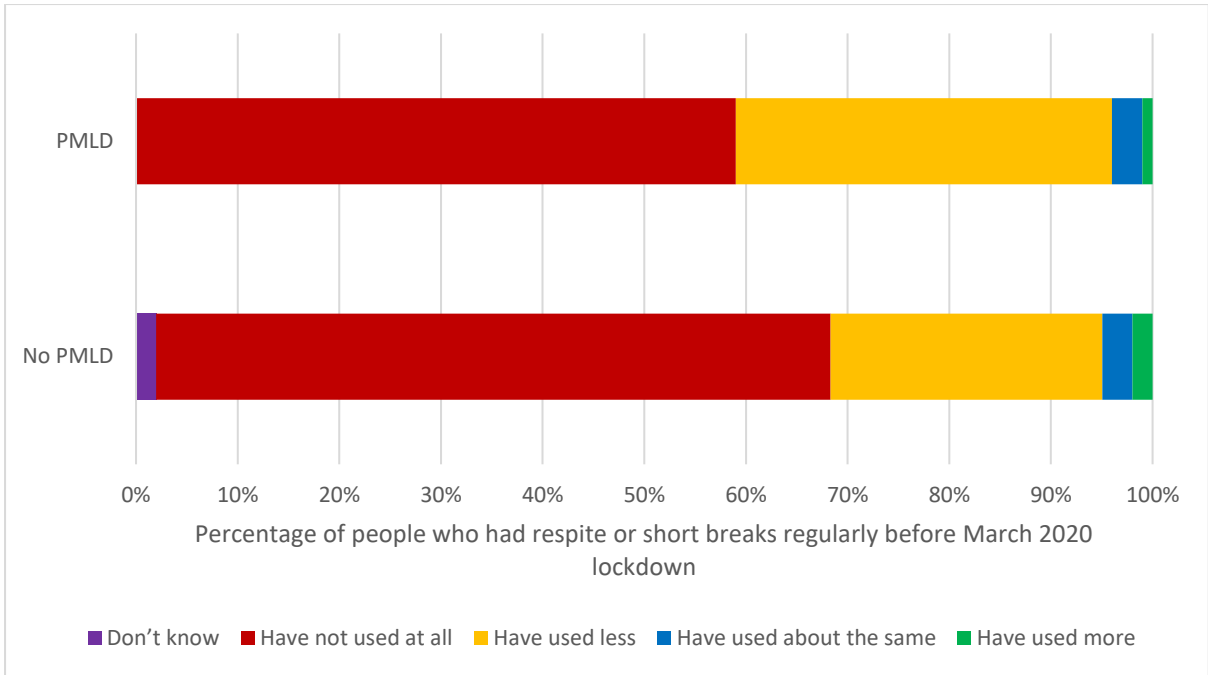


Figure 4.19. The percentage of people with learning disabilities who have had as many short breaks or respite as before the March 2020 lockdown (Sample: People with PMLD (n=71), People without PMLD (n=66))

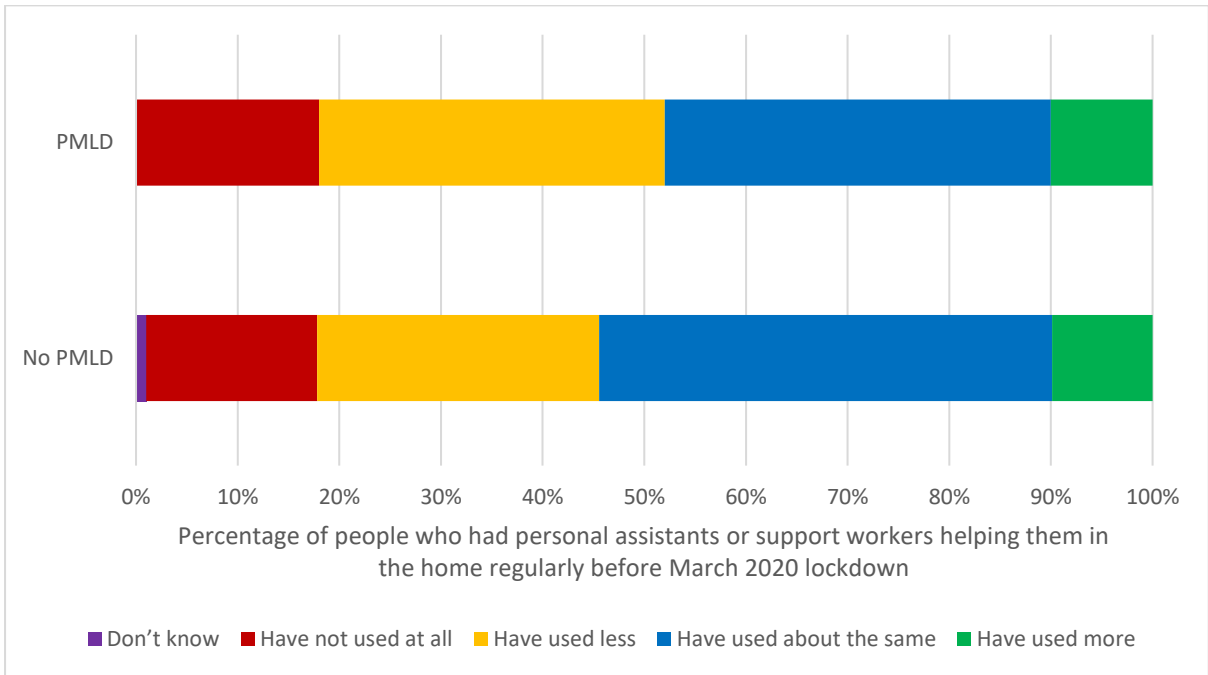


Figure 4.20. The percentage of people with learning disabilities who have had personal assistants or support workers helping them at as before the March 2020 lockdown (Sample: People with PMLD (n=112), People without PMLD (n=106))

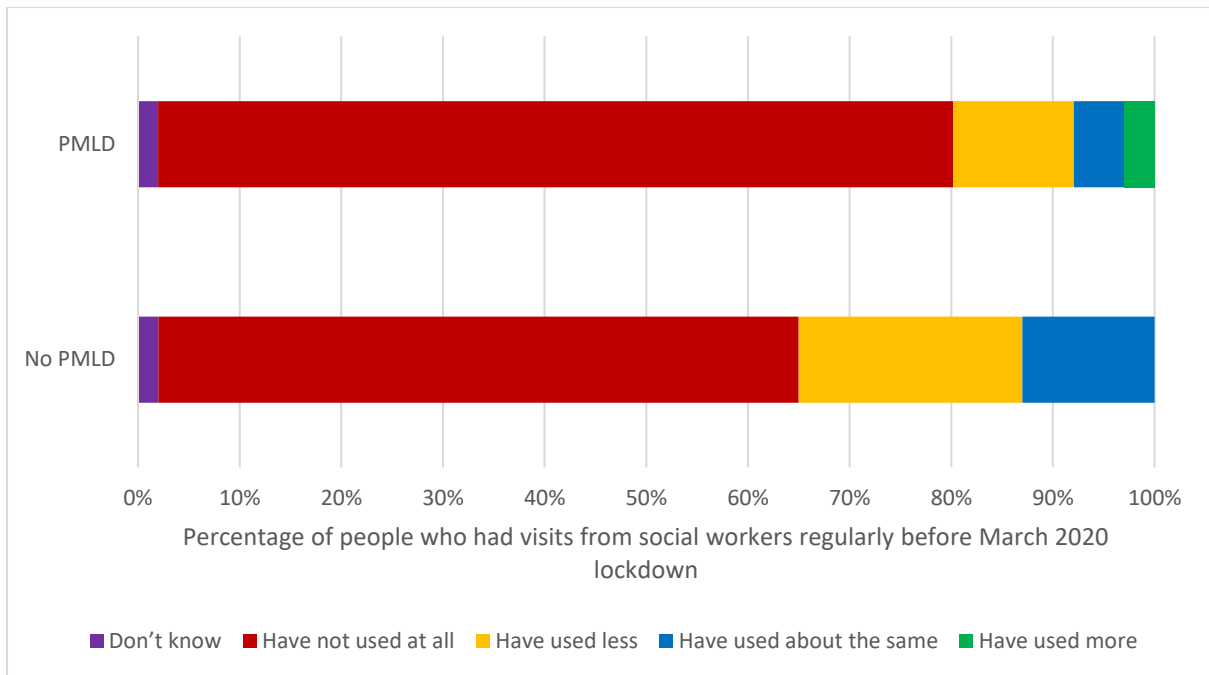


Figure 4.21. The percentage of people with learning disabilities who have received visits from social workers as before the March 2020 lockdown (Sample: People with PMLD (n=66), People without PMLD (n=68))

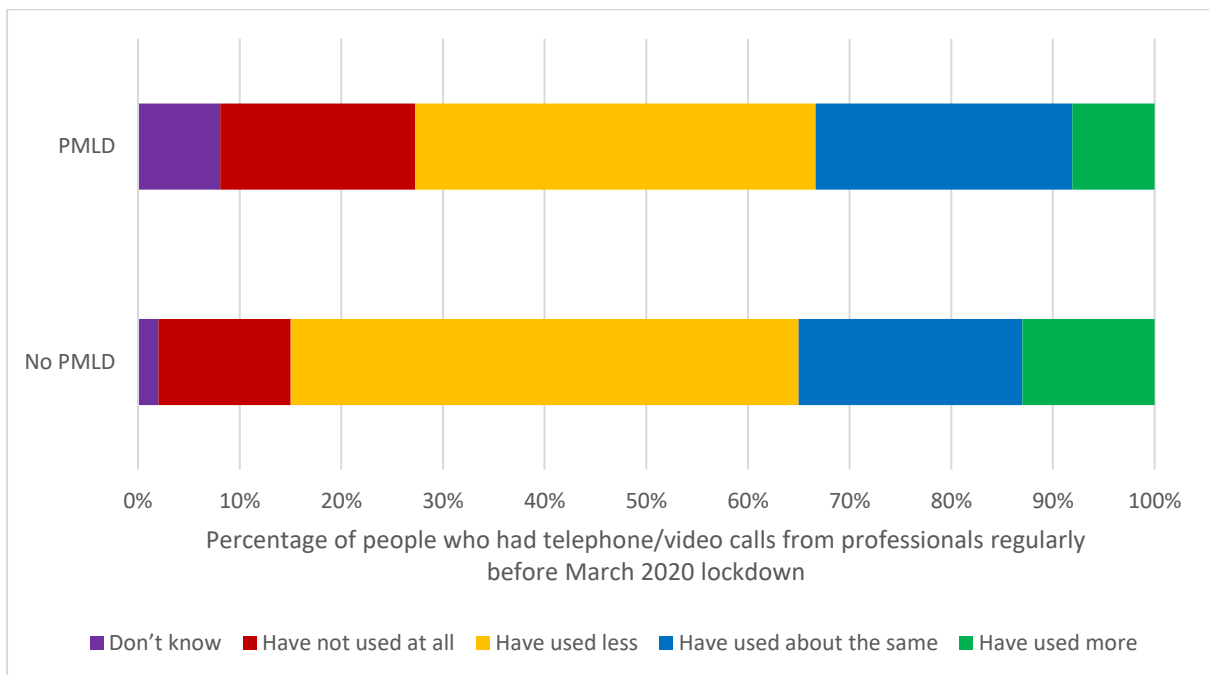


Figure 4.22. The percentage of people with learning disabilities who have got as much support from professionals like social workers / nurses / calling them by phone, computer or tablet rather than seeing them face to face (Sample: People with PMLD (n=36), People without PMLD (n=33))

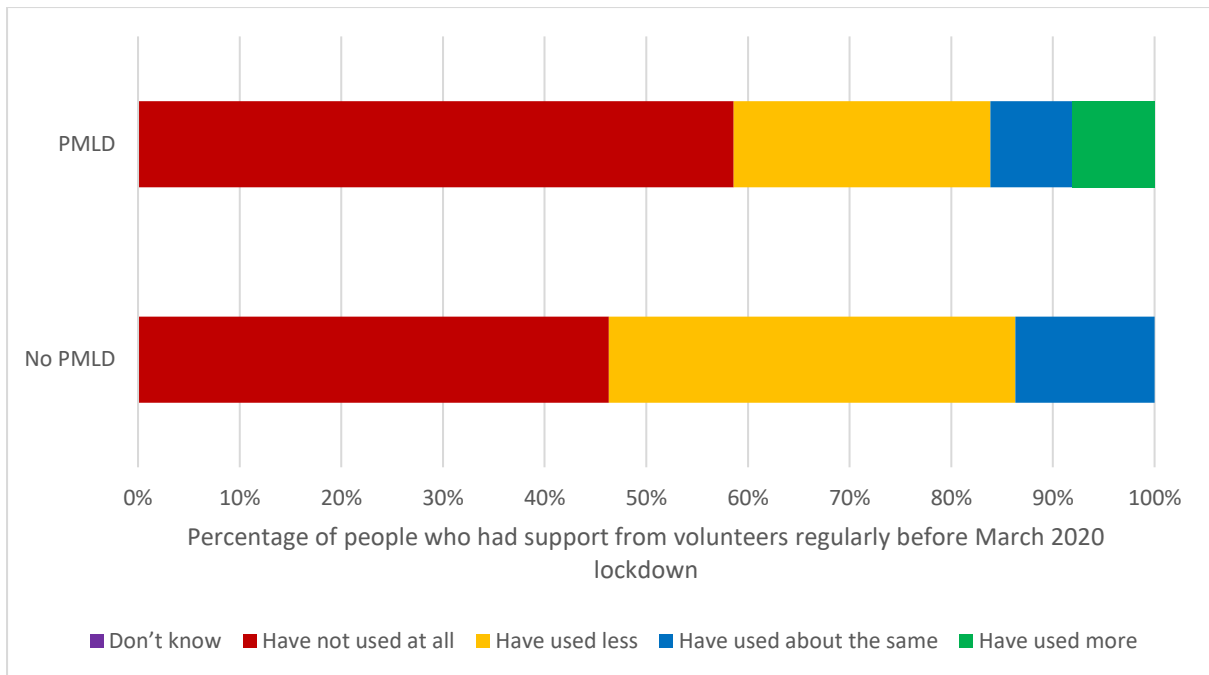


Figure 4.23. The percentage of people with learning disabilities who have got as much support from volunteers as before the March 2020 lockdown (Sample: People with PMLD (n=12), People without PMLD (n=23))

A substantial reduction in the amount of support received by people with and without PMLD was reported in Cohort 2 following the March 2020 lockdown. This was particularly the case for day services, with 97% of people with PMLD and 99% of people without PMLD having services reduced or stopped completely by the time of the surveys (Dec 2020 – Feb 2021). It was also reported that 98% and 99% of people with and without PMLD (respectively) have experienced their community activities stopping or reducing, and 96% and 94% of people with PMLD (respectively) had experienced a reduction or stopping of their short breaks or respite since the start of the first national lockdown in March 2020.

People with PMLD were reported to be 1.9 times more likely to have not been to day services and 2.4 times more likely to have not attended community activities, compared to people without PMLD ( $p = .02$ ,  $p = .01$ ).

## **4.7. Living circumstances, employment, and money**

In this sub-section, we report the findings from the Cohort 2 surveys about the living circumstances, employment, and money with learning disabilities during the COVID-19 pandemic, separated by whether the person completing the survey was caring for someone with or without PMLD. These are:

- how they are getting food,
- how they are getting their medications,
- whether they have access to outdoor space,
- about their employment, and
- about their finances.

### **4.7.1. Food**

Family carers/paid support staff answered questions about how the people with learning disabilities who they supported/cared for were getting food during the COVID-19 pandemic. The data from these questions are presented in Table 4.15, separated by whether the people with learning disabilities had PMLD or not.

Table 4.15. How is the person you support/care for getting food?

	<b>People with PMLD</b>	<b>People without PMLD</b>
<b>Through family</b>	51%	60%
<b>From the place they live in</b>	27%	19%
<b>Delivered from supermarkets</b>	18%	17%
<b>Shopping on their own</b>	7%	16%
<b>Through other people</b>	6%	3%
<b>Through friends or neighbours</b>	4%	1%
<b>From support organisations</b>	1%	5%
<b>From a food bank</b>	1%	2%
<b>Food parcels – they are shielding</b>	1%	1%
<b>Food parcels – person they live with is shielding</b>	1%	1%
<b>Finding it difficult to get food</b>	1%	1%

Our data indicate that only 1% of people with and without PMLD were finding it difficult to get food. People without PMLD were more likely to go shopping on their own (16%) than people with PMLD (7%); although both people with and without PMLD were most likely to get food from their family members (51% and 60% respectively).

### **4.7.2. Medications**

Family carers/paid support staff reported that 87% of people with PMLD and 76% of people without PMLD were taking medications. Table 4.16 displays data about how they were getting their medicines.

Table 4.16. Does the person you support/care for need medicines at the moment?

	People with PMLD	People without PMLD
<b>From family</b>	52%	54%
<b>Delivered from pharmacy/chemist</b>	25%	22%
<b>From the place they are living in</b>	20%	12%
<b>On own – from pharmacy/chemist</b>	9%	16%
<b>From friends/neighbours</b>	4%	1%
<b>With support – from pharmacy/chemist</b>	2%	1%
<b>Finding it difficult</b>	1%	1%
<b>Not getting medicines</b>	1%	1%

A very small number of people with and without PMLD were finding it difficult to get, or not getting, their medicines. For people with and without PMLD, it was relatively common for them to receive medicines from family (people with PMLD = 52%, people without PMLD = 54%), or have them delivered from the pharmacy/chemist (people with PMLD = 25%, people without PMLD = 22%).

#### 4.7.3. Access to outdoor space

We asked family carers/paid support staff about whether the people with learning disabilities they support/care for had easy access to outdoor space, and these data are presented in Table 4.17 separated by whether the person with learning disabilities had PMLD or not.

Table 4.17. Access to outdoor space for people with learning disabilities

	People with PMLD	People without PMLD
<b>Current home has outdoor space</b>		
Private garden	78%	74%
Shared garden	12%	17%
Balcony	2%	1%
Rooftop garden/terrace	1%	1%
Other outdoor space	5%	6%
No	4%	4%
<b>Access to outdoor open space (within 10-15 minute walk)</b>		
Yes	80%	83%
No	19%	16%
Don't Know	0%	1%

At least 90% of people with and without PMLD had access to a private or shared garden where they live, and at least 80% family carers/paid support staff also reported that the person they care for (in both people with PMLD and people without PMLD groups) had access to outdoor open space (e.g. a park or beach) within a 10 to 15 minute walk of where they live.

#### 4.7.4. Employment

Family carers/paid support staff reported that 12 people with PMLD (7%) had a paid job before the start of the first lockdown in March 2020 and, of these people, 8 (67%) were either still working or were furloughed. For people without PMLD, 49 (24%) were reported to have had a paid job before the start of the first lockdown in March 2020, and 29 of those people (59%) were either still working or were furloughed.

We also asked about the volunteer work. Family carers/paid support staff reported that 12 people with PMLD (8%) had volunteer work before the start of the first lockdown in March 2020. For people without PMLD, 44 (22%) were reported to have had a volunteer job before the start of the first lockdown in March 2020. Although only based on a small sample, 7 of the 12 (64%) people with PMLD who had a volunteer role before the start of the first lockdown in March 2020 had lost their role, compared to 12 of the 44 (28%) of people without PMLD.

#### 4.7.5. Money

Family carers/paid support staff were asked about the finances of the people they support/care for during the COVID-19 pandemic. These questions included whether people with and without PMLD had more or less money to spend, whether there had been any changes to benefits, and whether it had been easier or harder to pay household bills since the first lockdown in March. These data are presented in Figures 4.24-4.26.

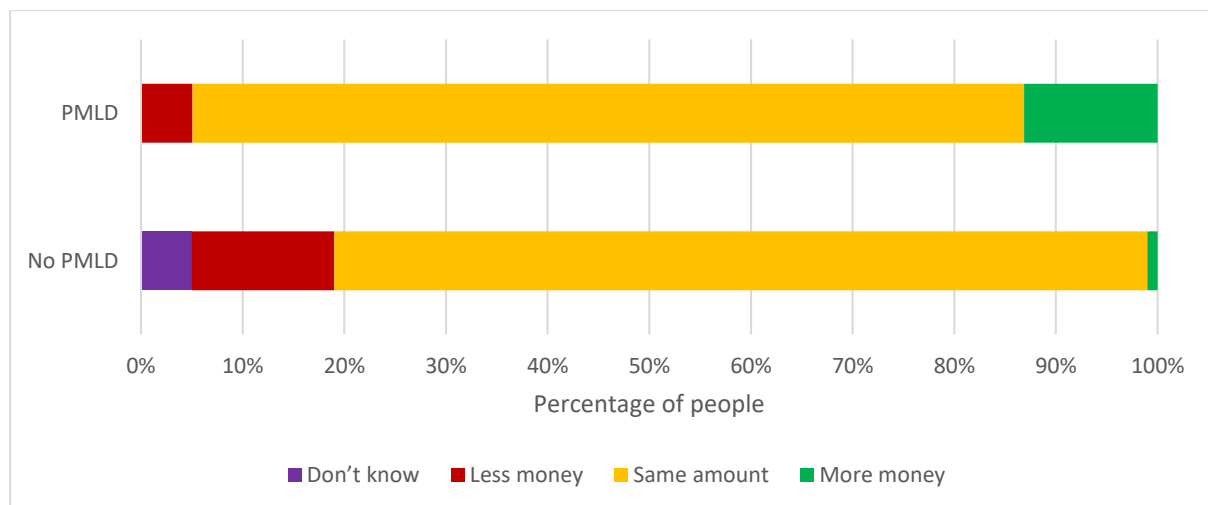


Figure 4.24. The amount of money people with learning disabilities have to spend compared to before the first lockdown in March 2020



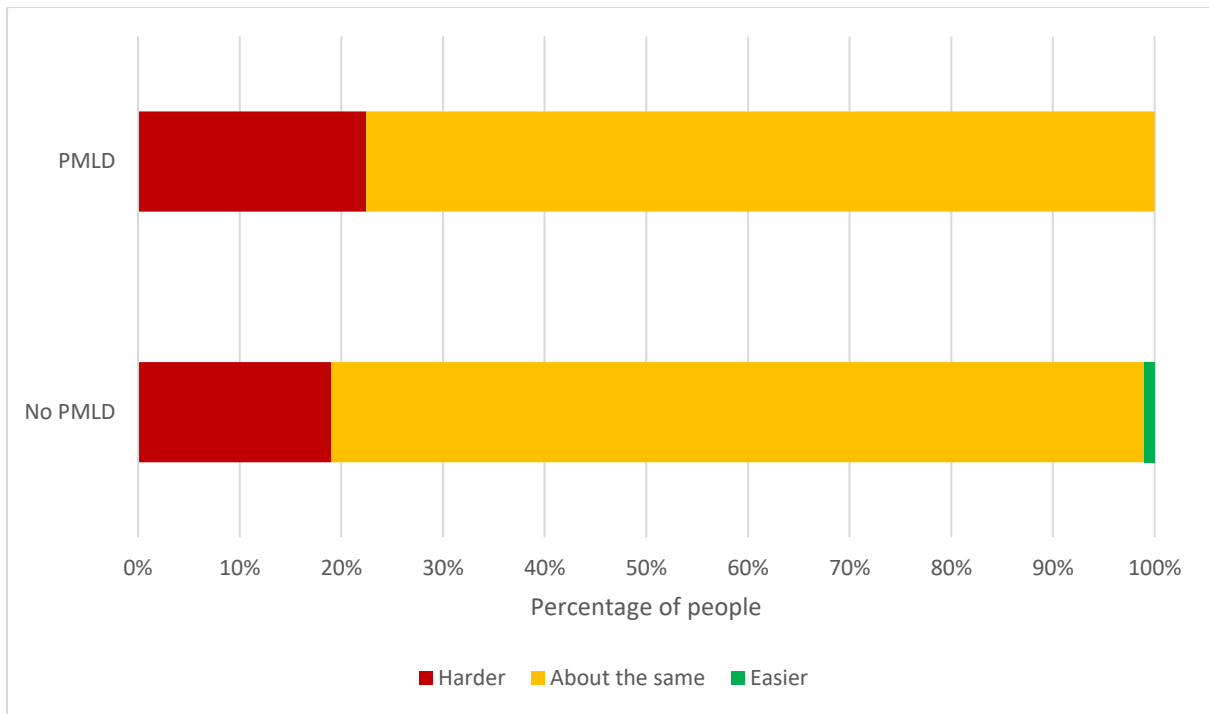


Figure 4.25. Has it been easier or harder for the household bills to be paid where the person you support/care for lives than before the start of the first lockdown in March 2020?

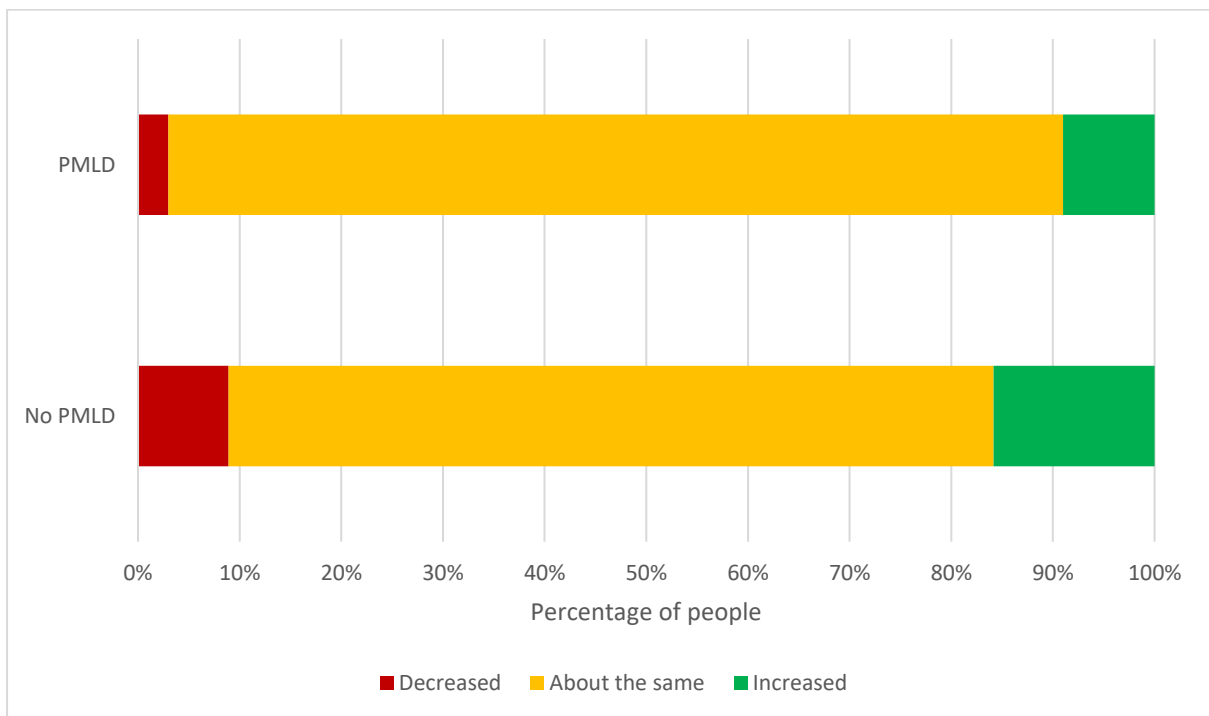


Figure 4.26. Has the amount of benefits the person you support/care for get changed the start of the first lockdown in March 2020?

The majority (81%) of people with PMLD have the same amount of money to spend now than they did before the first lockdown in March 2020, similar to the percentage of people without PMLD (80%) who have the same amount of money to spend now. When asked about how difficult it was for household bills to be paid in the place

where the people with and without PMLD were living, at least 75% of participants in Cohort 2 (across the groups) reported that the level of difficulty had not changed. When asked about benefits, participants in Cohort 2 (across both groups) responded that the amount of benefits that people with and without PMLD get had stayed about the same, although this percentage was higher for people with PMLD (88%) compared to people without PMLD (76%).

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