Coronavirus and People with Learning Disabilities Study

Wave 3 Results
September 2021

Full Report

Samantha Flynn, Nikita Hayden, Libby Clarke, Sue Caton, Chris Hatton, Richard P. Hastings, David Abbott, Stephen Beyer, Jill Bradshaw, Amanda Gillooly, Nick Gore, Pauline Heslop, Andrew Jahoda, Roseann Maguire, Anna Marriott, Edward Oloidi, Andreas Paris, Peter Mulhall, Katrina Scior, Laurence Taggart and Stuart Todd

Manchester Metropolitan University
WARWICK
THE UNIVERSITY OF WARWICK
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Study team:

Co-Primary Investigators: Professor Richard Hastings and Professor Chris Hatton

Co-Investigators: Prof David Abbott (University of Bristol), Dr Stephen Beyer (Cardiff University), Dr Jill Bradshaw (University of Kent), Dr Nick Gore (University of Kent), Prof Pauline Heslop (University of Bristol), Prof Andrew Jahoda (University of Glasgow), Anna Marriott (National Development Team for Inclusion), Prof Katrina Scior (UCL), Dr Laurence Taggart (Ulster University), Prof Stuart Todd (University of South Wales)

Partner organisations: All Wales People First, Learning Disability Wales, All Wales Forum of Parents and Carers of People with Learning Disabilities, Scottish Commission for Learning Disability, Promoting a More Inclusive Society (PAMIS), Positive Futures, Mencap Northern Ireland, Learning Disability England, PMLD Link, Positive Futures, CAN Northern Ireland, Families Involved in Northern Ireland (FINI).

Researchers: Dr Sue Caton (Manchester Metropolitan University), Libby Clarke (University of Warwick), Dr Samantha Flynn (University of Warwick), Dr Nikita Hayden (University of Warwick), Dr Amanda Gillooly (University of Glasgow), Roseann Maguire (University of Glasgow), Dr Peter Mulhall (Ulster University), Dr Edward Oloidi (University of South Wales), Andreas Paris (University of Warwick)

Report Contents

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[1]. 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 at least three times more likely than people without learning disabilities to die from COVID-19[2,3,4]. 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 three brief reports from the project[5].

Large-scale COVID-19 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 was designed to systematically and responsively track the experiences of adults with learning

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[1] 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)

[2] 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*

[3] ONS (2021). Updated estimates of coronavirus (COVID-19) related deaths by disability status, England: 24 January to 20 November 2020. 11 Feb 2021 https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/coronaviruscovid19relateddeathsbydisabilitystatusenglandandwales/24januaryto20november2020 (accessed 26 August 2021)

[4] Williamson E J, McDonald H I, Bhaskaran K, Walker A J, Bacon S, Davy S et al. Risks of covid-19 hospital admission and death for people with learning disability: population based cohort study using the OpenSAFELY platform *BMJ* 2021; 374 :n1592 doi:10.1136/bmj.n1592 (accessed 26 August 2021)

[5] 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/resultsjanuary21/coronavirus_and_people_with_learning_disabilities_emerging_issues_report_easy_read_v2.pdf
https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability/resultsjanuary21/covid-19_key_issues_brief_report_25.2.21.pdf
https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability/coronavirus_and_people_with_learning_disabilities_emerging_issues_may_report_easy_read.pdf (all accessed 26 August 2021)

disabilities through the COVID-19 pandemic over time across the UK, and investigate swiftly actionable factors associated with better outcomes.

This project was 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 have been three ‘Waves’ of data collection to capture differences and changes over time during the COVID-19 pandemic from the same cohorts of people. We have written about the findings from the first two Waves of data collection, and all findings are published on the study website[6].

There were two cohorts of participants: Cohort 1 was adults with learning disabilities who take part in an interview with a researcher, and Cohort 2 was 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 focused 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 describe the main results of the third Wave of the Coronavirus and People with Learning Disabilities Study. This report is intended as a reference source, and additional accessible versions of the findings will be produced separately and also 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 groups of people with learning disabilities and family carers of people with profound and

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[6] https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability/results/ (accessed 20 August 2021)

multiple learning disabilities (PMLD). We undertook this consultation in a number of steps:

1. We developed each interview and survey after asking people with learning disabilities and family carers from across the UK about the issues that were important to them
2. We asked partner groups in each country to provide their feedback on the drafted interview and/or survey
3. We consulted further with partner groups from across the UK about the interview and survey before we started data collection
4. We continue to routinely ask these partner 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?

For Waves 1 and 2, recruitment of people into the study was facilitated through multiple methods, including through collaborating organisations, social media, and wider networks of learning disability and family organisations across England, Northern Ireland, Scotland, and Wales. Potential participants could express interest in the study via telephone, email, social media, or clicking a link to the survey (for family carers and support staff only) on the project website[7].

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

1.2.4. How did we collect the data?

Data were collected between July and August 2021.

1.2.4.1. Cohort 1: Adults with learning disabilities

For Wave 3 of this study, we directly interviewed (via Zoom, telephone, Microsoft Teams, WhatsApp video call, Messenger video call, and FaceTime) 489 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.

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, 35 minutes to complete, and were usually completed in one sitting. Short breaks were offered during interviews when needed.

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[7] https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability (accessed 16 August 2021)

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 at Wave 3, participants were the family carers and paid support staff of 280 adults with learning disabilities.

1.2.5. How did we analyse the data?

1.2.5.1. Quantitative data

The analysis for Wave 3 reported here is descriptive, with percentage estimates relating to the responses for individual survey items. Data from Cohort 1 and Cohort 2 were analysed separately and some descriptive comparisons have been made between the two cohorts.

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 using 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 use <1% to signify such instances.

1.2.5.2. Qualitative data

There was 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 3 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. We have not presented a formal qualitative analysis of these responses to open-ended questions in this report. Such an analysis from Wave 1 of the study[8] is to be published in the *Tizard Learning Disability Review*, and a copy can be obtained from the study team.

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[8] Flynn, S., Caton, S., Gillooly, A., Bradshaw, J., Hastings, R. P., Hatton, C., Jahoda, A., Mulhall, P., Todd, S., Beyer, S., Taggart, L. and the Coronavirus and people with learning disabilities study team. (in press). The experiences of adults with learning disabilities during the COVID-19 pandemic. *Tizard Learning Disability Review*.

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

2.1. Who took part?

In Cohort 1, data were available for this report for 489 people with learning disabilities and, in Cohort 2, for 280 family carers or support staff of people with learning disabilities.

In the description below, we discuss the results from the two cohorts of the survey to provide 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. Information about the living circumstances of people with learning disabilities in Wave 3 is presented in Table 2.1.

Demographic data for participants who took part in Wave 1 can be found in the Wave 1 Full Report[9]. These questions were not asked of participants in Wave 3, and required data linkage from the Wave 1 databases. The priority for this report was to share a comprehensive set of findings from the Wave 3 survey as quickly as possible after data collection finished, so the data linkage was not completed for the purposes of this report. Based on our participant retention rates from Wave 1 (Cohort 1: 79% and Cohort 2: 74%), we anticipate that the demographic data will be broadly similar. Other published work that draws on the Wave 3 data will present results following data linkage.

At Wave 1, 621 people with learning disabilities took part in Cohort 1 and 378 family carers or support staff of people with learning disabilities took part in Cohort 2. The number of men and women in both cohorts at Wave 1 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. In Cohort 2 at Wave 1, 83% of participants were family carers, 15% were support workers or paid carers, and 3% had another relationship (e.g., friend) to the person with learning disabilities.

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[9] https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability/results/wave1results/fullreport/coronavirus_and_people_with_learning_disabilities_study_wave_1_full_report_v1.0_final.pdf

Table 2.1. Who people with learning disabilities live with (Wave 3 participants)

	Cohort 1	Cohort 2
Who does the person with learning disabilities live with?		
Live alone with no support from staff	9%	
Live alone with support staff coming into their home (supported accommodation)	20%	10%
Live with their partner with no support from staff	3%	
Live with their partner with support staff coming into their home	2%	
Live with family with no support from staff	33%	37%
Live with family with support staff coming into their home	5%	21%
Live in Supported/independent living, but have moved back to family home because of COVID-19	1%	
Live in a Shared Lives arrangement	3%	1%
Live with other people with learning disabilities with no support from staff	0%	
Live with other people with learning disabilities with support staff coming into their home during the day	4%	
Live with other people with learning disabilities with support staff coming into their home during the day and night	20%	
Live with other people in supported living accommodation		13%
Live with other people in residential care		9%
Live in a secure placement		1%
Live in a different type of home (e.g., residential college)		7%
The person with learning disabilities looks after someone they live with (N = 35)	10.3%	

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

The majority of people with learning disabilities in Cohort 1 lived alone (29%) or with their family (38%), 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. In Cohort 1, 35 people with learning disabilities who reported that they look after someone who they lived with. This ranged from their parents, children, partner, and other people (e.g., friends, other family members).

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,
- COVID-19-related restrictions,
- tests for COVID-19,
- whether they had had COVID-19,
- whether they had been hospitalised because of COVID-19 symptoms,
- whether they were 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, and
- about COVID-19 vaccinations.

2.2.1. Information and rules about COVID-19

We asked participants in Cohort 1 whether it had been easy to find good and accurate information about COVID-19 in the last four weeks. These data are found in Figure 2.1 below.

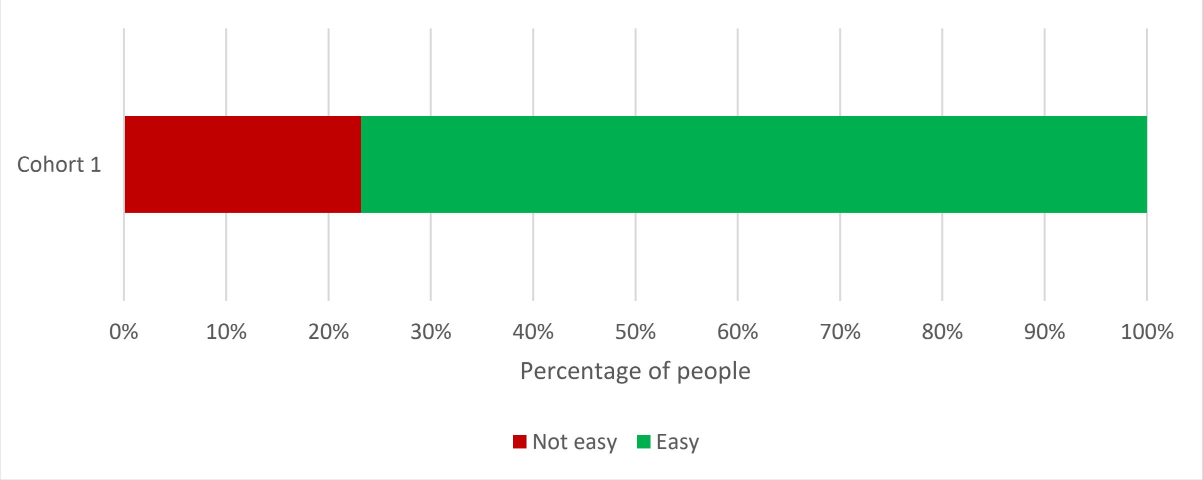

Figure 2.1. In the last four weeks, has it been easy for you to find good information about COVID-19 that you understand? (Cohort 1 only)

Figure 2.1 shows that most people in Cohort 1 (76%) 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 2.2.

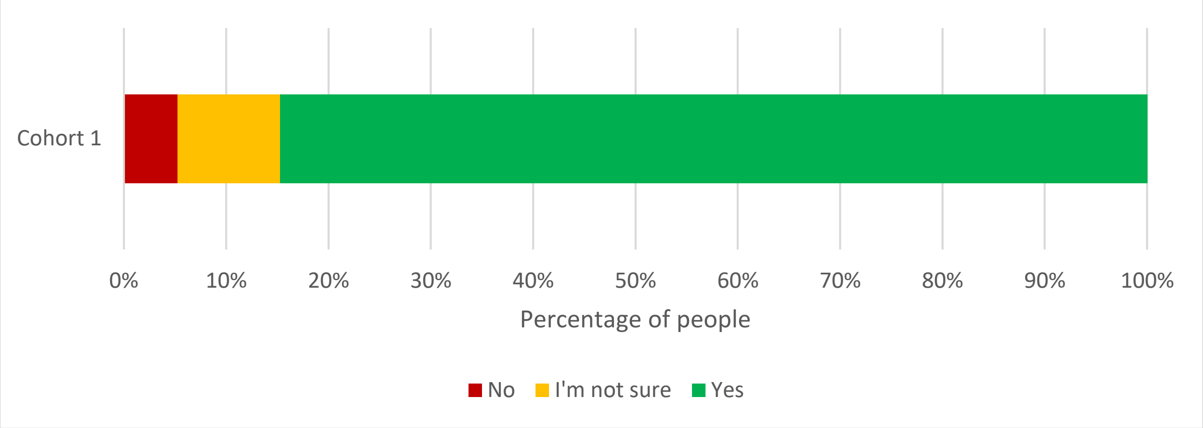

Figure 2.2. Do you know what the rules are now where you live about COVID-19 and social distancing? (Cohort 1 only)

Figure 2.2 indicates that the vast majority (84%) 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 in the last four weeks. These data are presented in Figure 2.3.

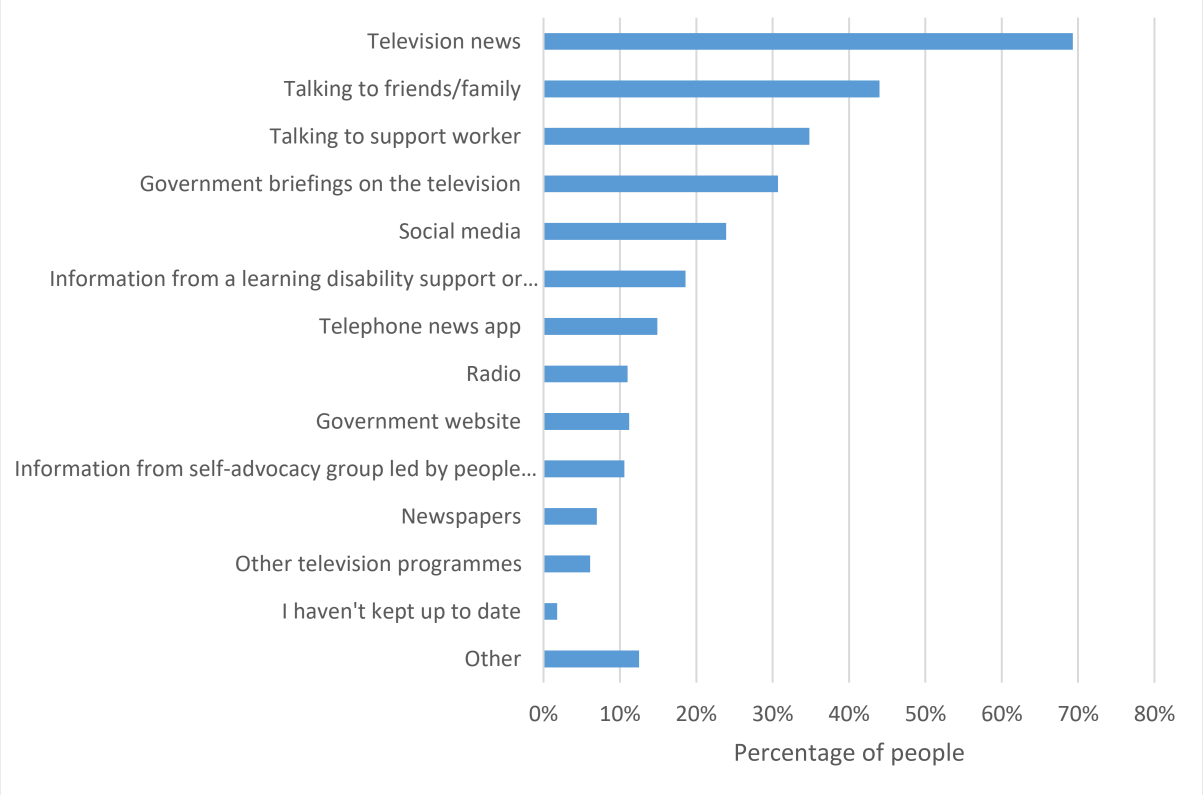

Figure 2.3. In the last four weeks, how have you found out about changes to COVID-19 rules? (Select all that apply) (Cohort 1 only)

The majority of people in Cohort 1 found out about changes to COVID-19 rules by watching the television news (69%) or by talking to their friends and family (44%) or support workers (35%). Of all the ways that people with learning disabilities in Cohort 1 found out about changes to COVID-19 rules, the majority of people said that the best way to find out about changes in the last four weeks was watching the television news (29%). Figure 2.4 below outlines the best ways to find out about changes to COVID-19 rules, as reported by people with learning disabilities in Cohort 1.

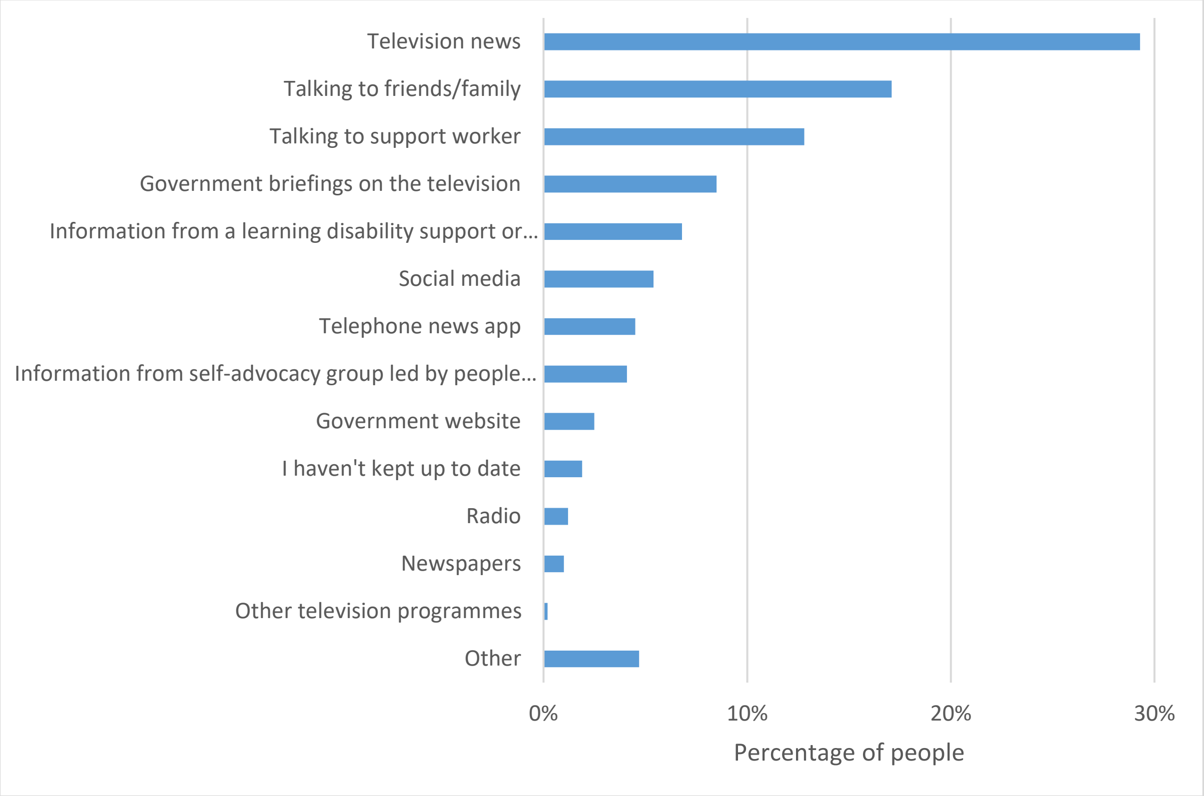

Figure 2.4. In the last four weeks, which ONE of these has been the best way to find out about changes to COVID-19 rules? (Cohort 1 only)

The best way for people with learning disabilities to find out about changes to COVID-19 rules was television news (29%), followed by talking to friends and family (17%), and talking to a support worker (13%).

2.2.2. COVID-19 restrictions

We asked participants in Cohort 1 about whether they thought there should be any restrictions (like wearing face masks or social distancing) right now on what people can do because of COVID-19. These data are displayed in Figure 2.5 below.

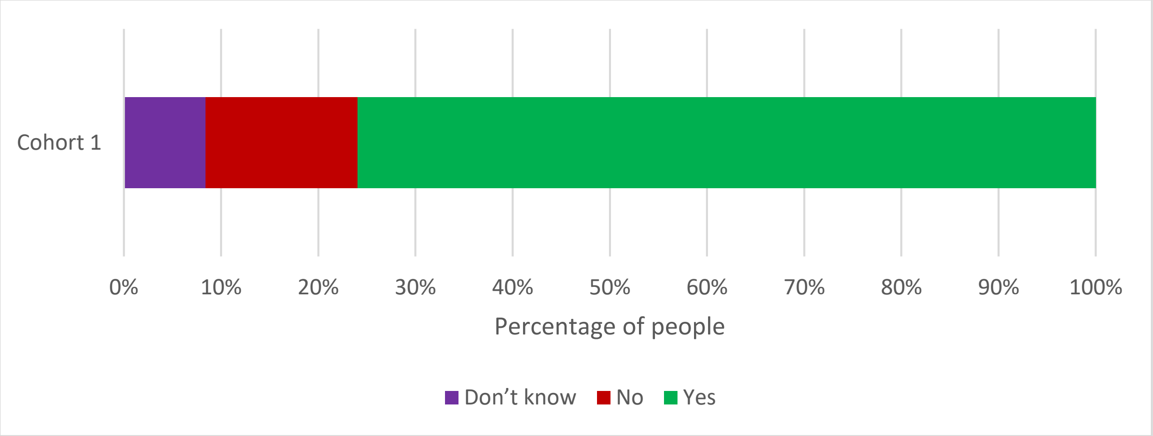

Figure 2.5. Do you think there should be any restrictions, like wearing face masks or social distancing, right now on what people can do because of COVID-19?

The majority (76%) of people with learning disabilities in Cohort 1 said that there should be COVID-19-related restrictions right now.

2.2.3. Testing for COVID-19 and having COVID-19

We also asked whether people with learning disabilities had been tested for COVID-19 in the last four weeks. 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. The percentage of people in both cohorts who had had a COVID-19 test is displayed in Table 2.2.

Table 2.2. Testing for COVID-19 in the last four weeks

	Cohort 1	**Cohort 2**
Yes – a Lateral Flow Test at home	26%	26%
Yes – a PCR test at home	7%	6%
Yes – a test at home, but unsure of what type	1%	2%
Yes – at a testing centre	4%	3%
No	61%	58%
Don't know	2%	5%

The majority of people with learning disabilities in both cohorts (<58%) had not had a COVID-19 test in the last four weeks. Where tests had been done at home, we asked about the frequency of these tests. These data are displayed in Figure 2.6 below.

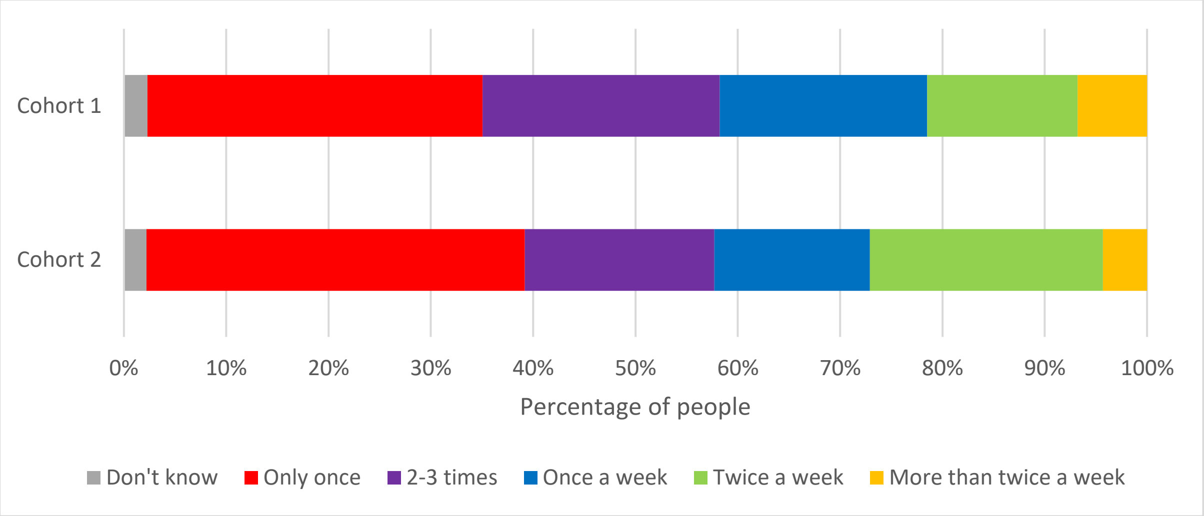

Figure 2.6. In the last four weeks, how many times have you/they had a test at home? (Sample: Cohort 1 = 164; Cohort 2 = 97)

The most commonly reported frequency of tests in Cohort 1 and 2 was only once (33% and 37% respectively). We also asked about how the tests were done, and these data are displayed in Table 2.3 below.

Table 2.3. How was the test done? (Select all that apply)

	Cohort 1 (n=164)	**Cohort 2 (n=97)**
Taught themselves how to do it	28%	5%
Someone showed them how to do it	40%	7%
A family member did it for them	13%	44%
A support worker/paid carer did it for them	34%	36%

In Cohort 1, the most frequently reported answer was that someone showed them how to do it (40%). In Cohort 2, the most frequently reported answer was that a family member did it for them (44%).

Reasons for people with learning disabilities having a COVID-19 test are included in Figures 2.7 and 2.8 below.

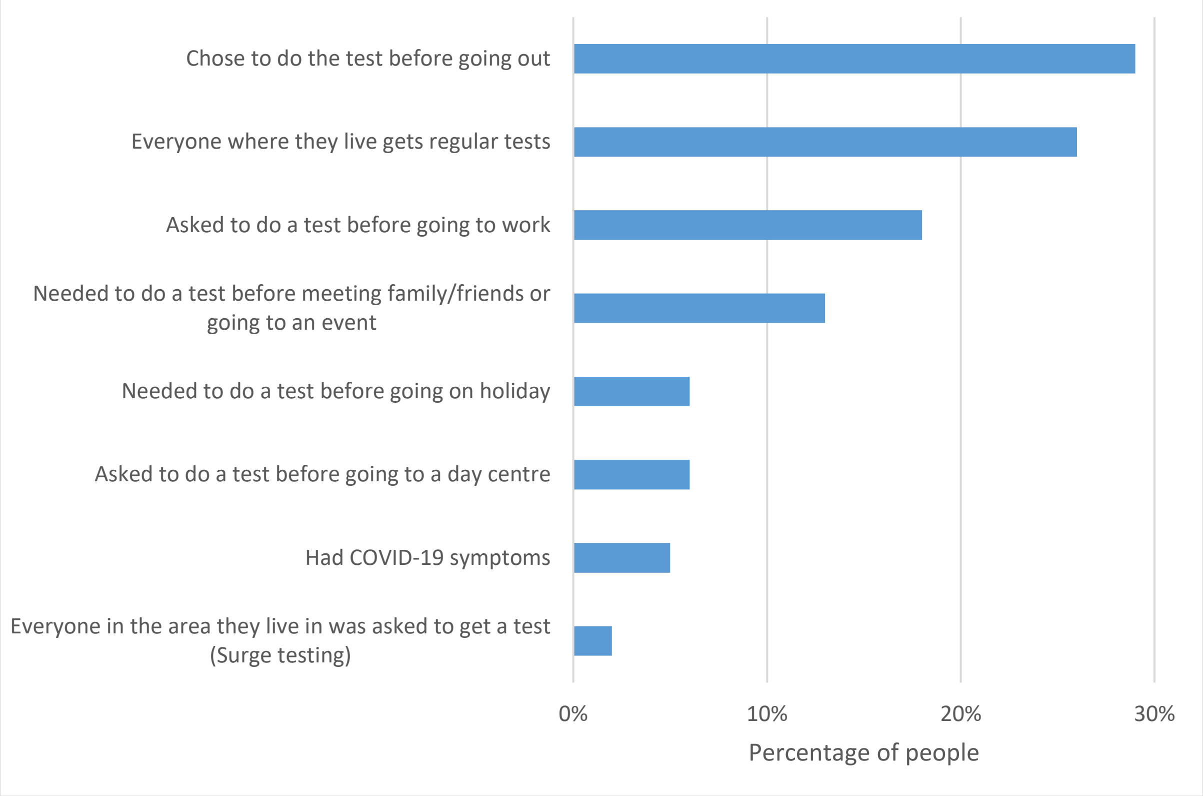

Figure 2.7. Reasons for doing COVID-19 tests (Select all that apply) (Cohort 1 only; n = 164)

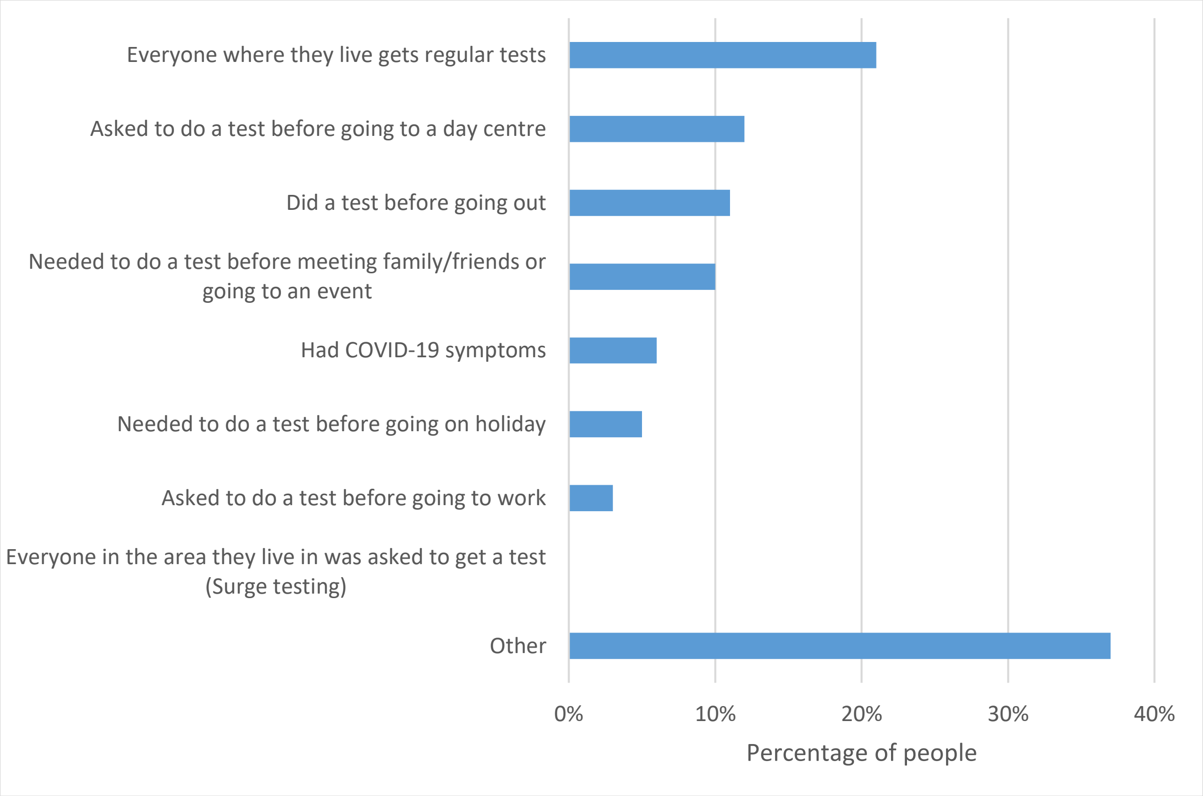

Figure 2.8. Reasons for doing COVID-19 tests (Select all that apply) (Cohort 2 only; n = 97)

The most frequently reported reasons for doing a COVID-19 test in Cohort 1 were that people chose to do a test before going out (29%), everyone where they live gets tested regularly (26%), and they were asked to do a test before going to work (29%). In Cohort 2, the most frequently reported reasons for doing a COVID-19 test were everyone where they live gets tested regularly (21%), they were asked to do a test before attending a day centre (12%), and they did a test before going out (11%). There was a high percentage of people in Cohort 2 who selected the ‘Other’ option, with some of the most frequently typed open-text responses including: to access respite care, someone close to them had tested positive recently, to visit friends and family, before going to school, and that they tested regularly as a habit.

We asked participants in both cohorts how they (Cohort 1), or the person they support (Cohort 2) got on doing the test, and selected quotes are included in Boxes 2.1 and 2.2 below.

“It made me choke. I always get that.”

“I find it okay, it can irritate my throat but it is okay. Someone showed me quickly and then I was fine with it. Sometimes I help my friend do it too.”

“I hate it, but it is essential so I do it.”

“I thought this was tricky, there are 5 different bits to it and I got a bit confused and anxious as to what I was doing with each bit and if I was doing right. I did it with my carer because I wanted some help. A one sheet easy read would have been really useful for this to be able to be more independently.”

“It’s a worry that you do it right, as if you don’t you might not be getting the right result and putting people unknowingly at risk.”

“Pretty well - it seemed simple enough and it was negative."

"I think it is important to do it, It's one of the fastest way to find out if it's okay. If you want to do things you need to do a test more often and it should be part of life now. It was okay, it doesn't feel nice but it's okay. But it helps myself and people so we should do it."

"I was sick when the nurse did the test on me."

"The first one was quite hard because I had to keep reading the instructions to see what I needed to do, but yeah I’m okay doing it. I do it because I want to make sure I’m safe."

"They are a nightmare because they want you to do the back of the throat and you retch and it's not nice."

“I asked a chemist how to do it. I made a video of how to do it for people with learning disabilities to go on our website. It tickled the nose and you have a timer. It’s easy.”

“The test was difficult, I sneezed and was uncomfortable. I was nervous getting the test done.”

Box 2.1. How did you get on doing the test? (Cohort 1 only)

Many of the responses to this question were positive in some way, with participants either recognising that the test was needed to keep them, and others safe, or reporting that the test was straightforward. Some participants noted that they had some difficulties doing the test, either through not being able to understand the instructions (which were not in Easy Read) or because of difficulties with actually doing the test (e.g., irritation, being sick). Some participants highlighted the need for Easy Read information, or videos, about testing procedure to be shared with people with learning disabilities.

"Better than the only other time she had one. She didn't have the tonsil bit of the test, just two nostrils and not really for that long, but at least she tolerated it and got a result."

"Fine. He's used to it now, and it helps his housemates to see him doing it confidently."

"He does not like it but understands a little so we can have his disabled twin home for visit from his care home."

"He finds it very uncomfortable and we have to struggle to do the test properly. Usually need more than one person to support him when carrying out the test."

"He manages the test himself and is quite relaxed about it now, after struggling at first."

"He's fine - he sees everyone else including the support staff doing it."

"It was very uncomfortable for them and due to their capacity they were reluctant in allowing staff to fully carry the test out."

"Not as bad as I'd expected. She 2 nurses came in full PPE. My daughter was very wary of them however they were very quick, swabbing her nostrils only. It was over quickly before she had time to get anxious and react."

"She didn't like it. I wasn't able to get a swab from the throat. I wasn't able to do the full 10 seconds in the nostril as she pulled my hand away."

"She was happy as mum had one first."

"Surprisingly well."

Box 2.2. How did the person you support/care for get on doing the test? (Cohort 2 only)

Many participants in Cohort 2 reported that the person they support/care for struggled to have the test done, with many people reporting that it was easier without having to take the throat swab. Some participants noted that having someone else there to model the behaviour was useful for some people with learning disabilities, as was being quick so that the person did not get overly anxious about it. Other participants reported that the person they support/care for has become practiced, or understood the reasons for them having to do the test.

We asked both cohorts about whether they thought that they (Cohort 1), or the person they support/care for (Cohort 2), had ever had COVID-19. 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 2.9 and 2.10.

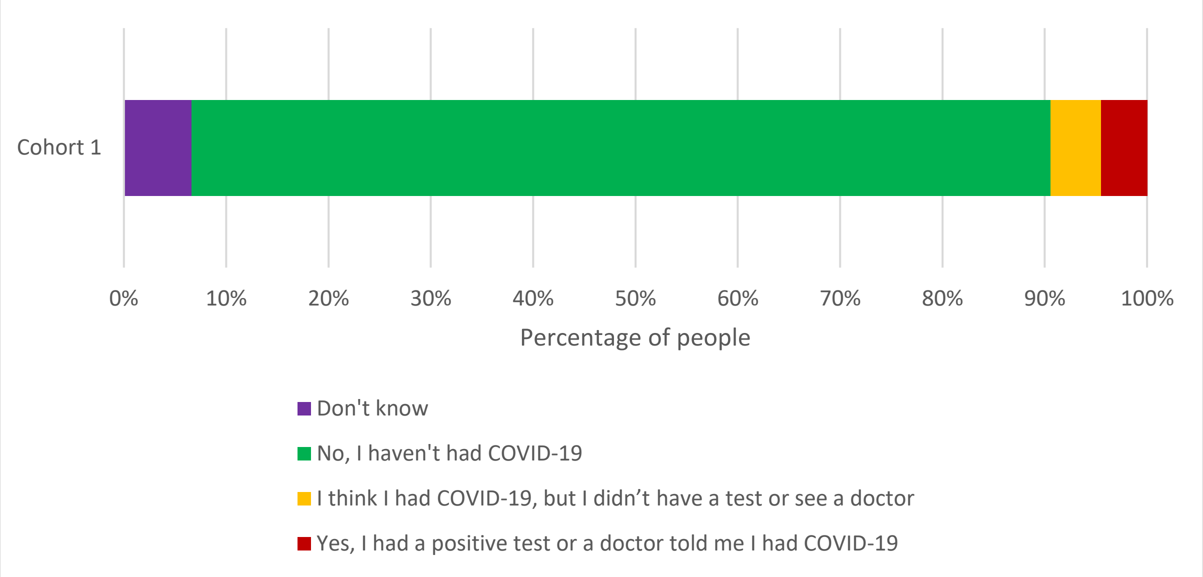

Figure 2.9. Do you think you have had COVID-19? (Cohort 1 only)

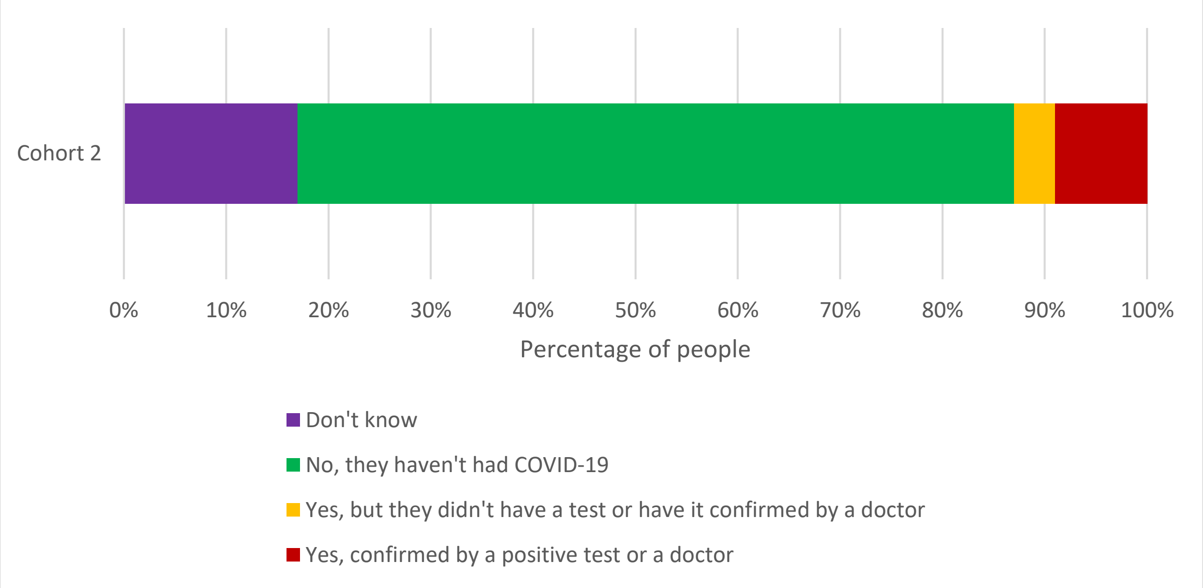

Figure 2.10. Do you think the person you support/care for ever had COVID-19? (Cohort 2 only)

In total, around one in ten people with learning disabilities within our sample were confirmed or were thought to have had COVID-19 (Cohort 1 = 10%, Cohort 2 = 13%).

Of those 46 people with learning disabilities in Cohort 1 who had had, or thought that they had had, COVID-19, nine (2%) had been hospitalised because of their COVID-19 symptoms. In Cohort 2, of the 36 people with learning disabilities who had a confirmed or suspected case of COVID-19, nine (3%) were hospitalised because of their COVID-19 symptoms.

2.2.4. Shielding and self-isolating

We asked both cohorts about whether they (Cohort 1) or the person they support/care for (Cohort 2) were currently shielding. These data are presented in Table 2.4.

Table 2.4. Current shielding

	Cohort 1	**Cohort 2**
Yes – told by a doctor or letter to shield	1%	13%
Yes – self-imposed "shielding"	2%	6%
No	97%	80%
Don't know	<1%	1%

Overall, 3% of people with learning disabilities in Cohort 1 and 19% of people with learning disabilities in Cohort 2 were shielding at the time of their interview or survey completion.

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.

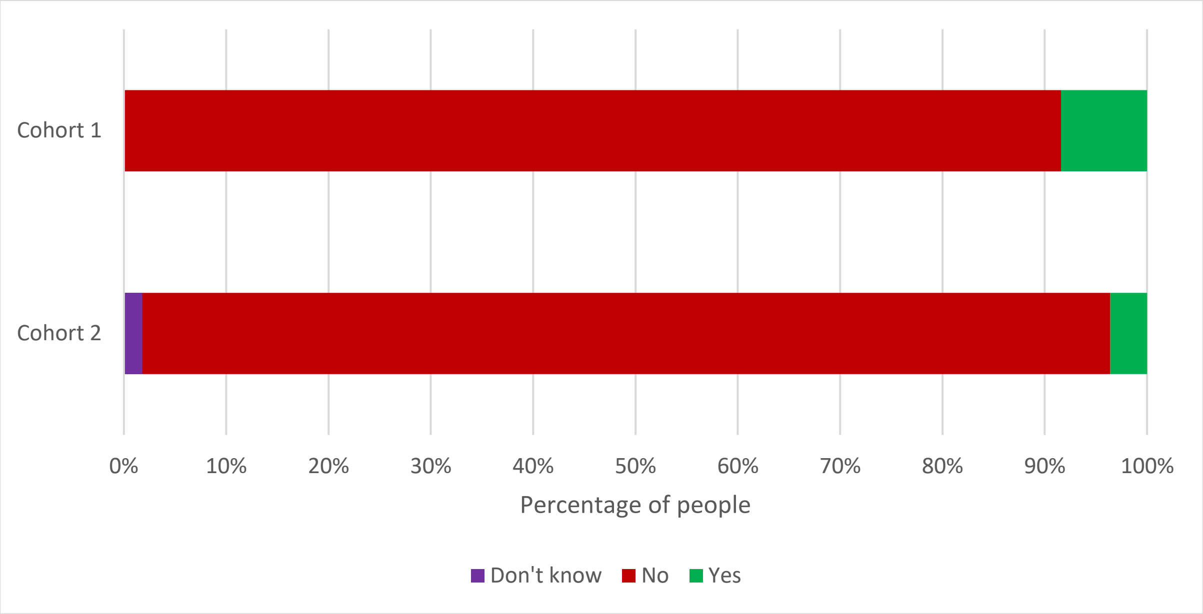

Figure 2.11. Person with learning disabilities self-isolated in the last four weeks because of COVID-19 symptoms or close contact with someone who had COVID-19 symptoms

The vast majority of people with learning disabilities in both cohorts (Cohort 1 = 92%, Cohort 2 = 95%) had not self-isolated.

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

We asked people in both cohorts whether family carers/paid support staff wore PPE when in close contact with 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
Yes	61%	46%
No	39%	52%
Don’t know		2%

In Cohort 1, family carers/paid support staff of people with learning disabilities were more frequently reported to wear PPE (e.g., masks, gloves, aprons) than in Cohort 2 (61% versus 46%).

We also asked whether people with learning disabilities had worn a face mask/covering when they were going out in the last week. These data are presented in Table 2.6.

Table 2.6. Use of face masks/coverings by people with learning disabilities in the last week

	Cohort 1	Cohort 2
Yes – worn a face mask/covering all the time when they were out	23%	24%
Yes – worn a face mask/covering when they were inside (e.g., a shop, a bus or a restaurant)	65%	32%
No – not worn a face mask/covering when they were out	1%	7%
No – not worn a face mask/covering because they can’t wear them (e.g., intolerance)	10%	29%
No – not worn face mark/covering because they have not been close to other people while out	<1%	4%
Not been out in last week	1%	4%

Fewer people with learning disabilities in Cohort 2 (56%) had been wearing face masks/coverings than people in Cohort 1 (88%), even accounting for the larger proportion of people with learning disabilities in Cohort 2 who had not been out in the last week. This may be explained by findings in Wave 1[10] 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%).

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[10] https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability/results/wave1results/fullreport/coronavirus_and_people_with_learning_disabilities_study_wave_1_full_report_v1.0_final.pdf (Accessed 20 August 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 3 was about COVID-19 vaccinations. We asked participants in both cohorts about whether the person with learning disabilities had received a COVID-19 vaccination. These data are displayed in Figure 2.12.

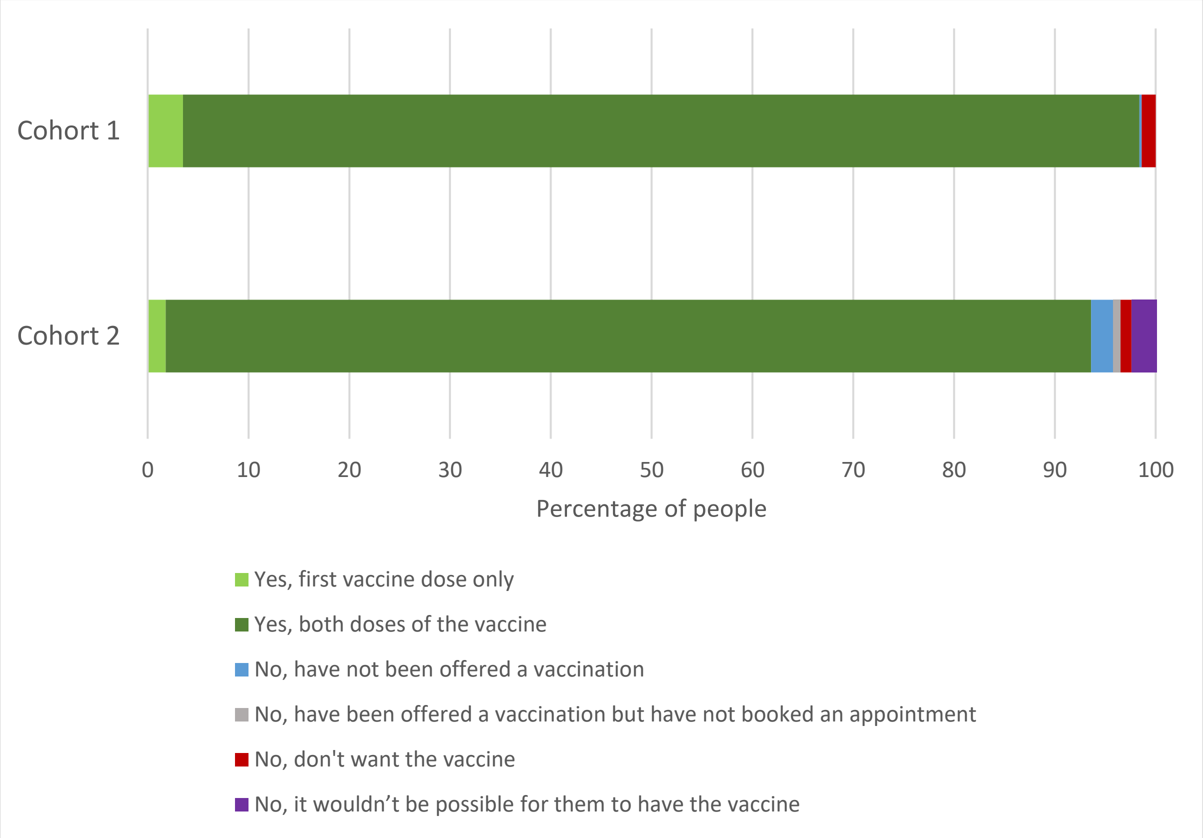

Figure 2.12. COVID-19 vaccination receipt in people with learning disabilities and reasons for non-receipt

The vast majority of participants in both cohorts (>92%) reported that they (Cohort 1), or the person they supported/cared for (Cohort 2), had received both doses of the COVID-19 vaccination.

When asked about whether they (Cohort 1) or the person they support/care for (Cohort 2) would take a booster COVID-19 vaccination in Autumn/Winter 2021, if this were needed, the vast majority of participants in both cohorts (>87%) indicated that they, or the person they supported/cared for, would be willing to have this.

We asked participants in both cohorts about whether they thought that all paid staff supporting them should have a COVID-19 vaccination. These data are displayed in Figure 2.13.

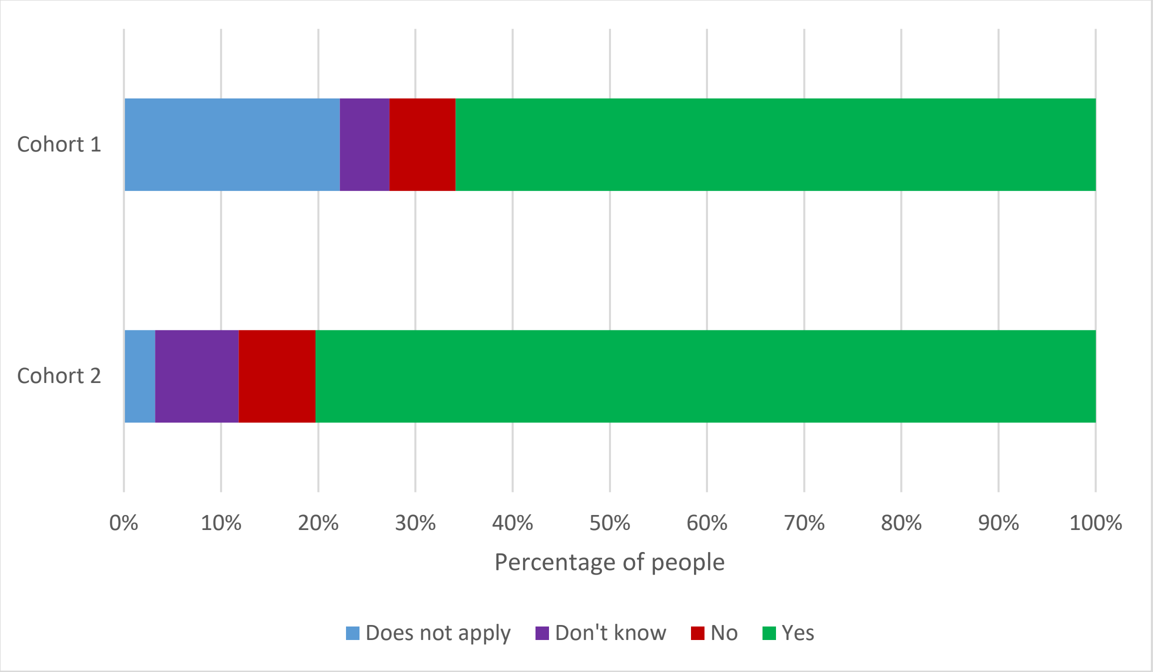

Figure 2.13. Do you think that all the support staff and PAs who support you/the person you support/care for should HAVE to have the COVID-19 vaccination?

For those for whom it applied, family members/paid support staff of people with learning disabilities in Cohort 2 reported to a similar level (83%) to people with learning disabilities in Cohort 1 to whom in applied (85%) that they thought that their paid support staff and PAs should have to have a COVID-19 vaccination.

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,
- contact with healthcare professionals,
- what has happened to planned medical tests, appointments and operations, and
- what is happening with annual health checks.

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

	Cohort 1	Cohort 2
Health today		
Good	65%	47%
OK	31%	37%
Not very good	4%	
Not good		16%
Don’t know		1%
New or worsening health conditions in the last four weeks (excluding COVID-19)		
Yes	19%	28%
No	80%	70%
Don’t know	<1%	2%
Prefer not to say	<1%	

When asked about their general health today, people with learning disabilities in Cohort 1 most commonly rated their health as good (65%), and this was slightly lower for Cohort 2, where 47% of participants reported health as good for the person with learning disabilities they supported/cared for.

Of the 93 people with learning disabilities in Cohort 1 who had a new or worsening health condition in the last four weeks (excluding COVID-19), 67% reported that they had tried to get advice from a doctor, nurse, or pharmacist. In Cohort 2, of the 76 people with learning disabilities who had a new or worsening health condition in the last four weeks (excluding COVID-19), 86% were reported to have sought advice from a doctor, nurse, or pharmacist.

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

Table 2.8. In the last four weeks, has the person you support/care for had a hospital admission for a reason not related to COVID-19? (Cohort 2 only)

	Cohort 2
Yes	5%
No	95%
Don't know	<1%

Of the 14 people with learning disabilities reported about in Cohort 2 who had been admitted to hospital for a reason unrelated to COVID-19 in the last four weeks, 93% 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 in the last four weeks, and these data are presented in Figure 2.14.

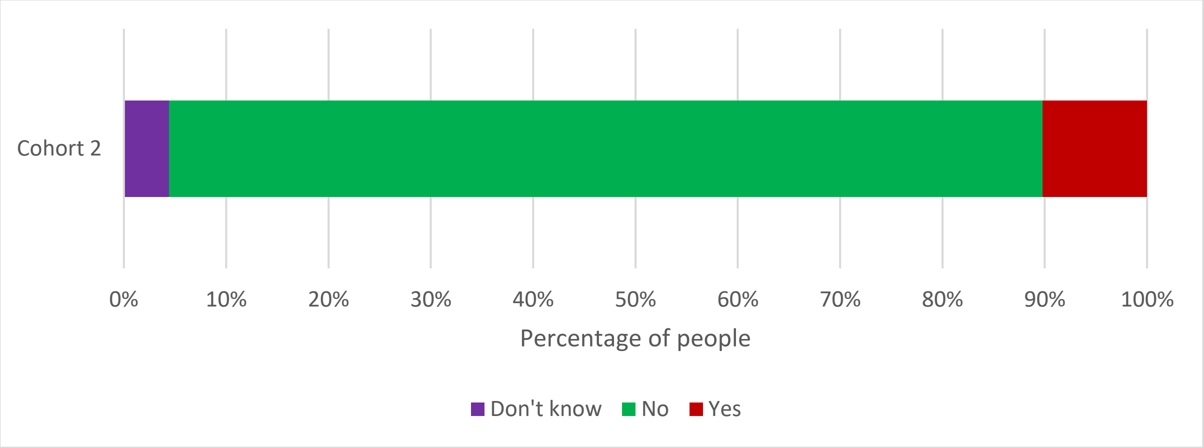

Figure 2.14. In the last four weeks, have there been difficulties getting and keeping essential equipment and resources for the person you support/care for? (Cohort 2 only)

In the four weeks before completing the survey, 10% of participants in Cohort 2 had had difficulties in getting and keeping essential equipment for the person they care for.

2.3.2. Contact with healthcare professionals

The following figures (Figures 2.15-2.18) present data about whether people with learning disabilities had had contact with healthcare professionals in the four weeks before the interview or survey.

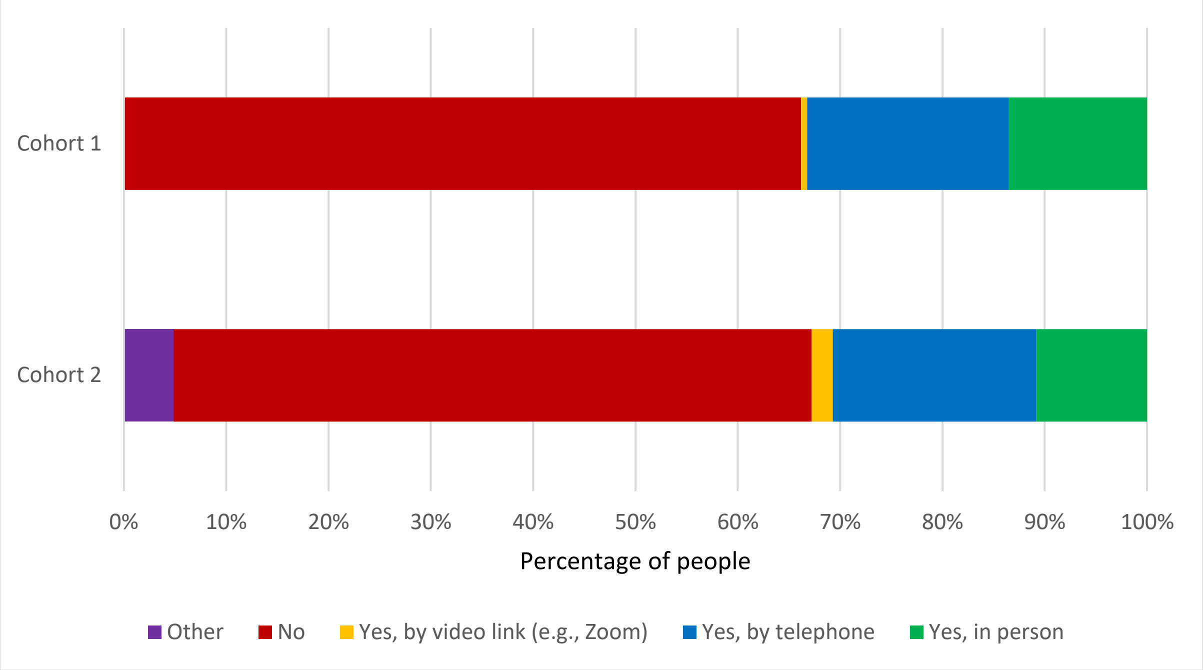

Figure 2.15. In the last four weeks have you/the person you support/care for been in contact with a GP?

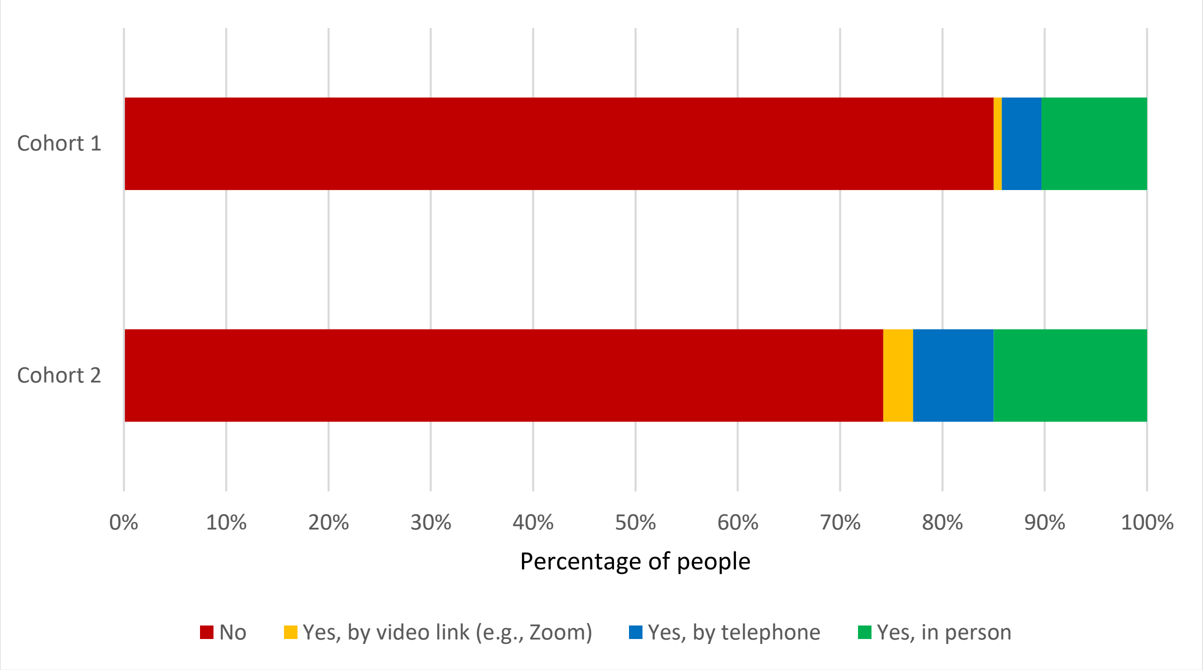

Figure 2.16. In the last four weeks have you/the person you support/care for been in contact with a community nurse?

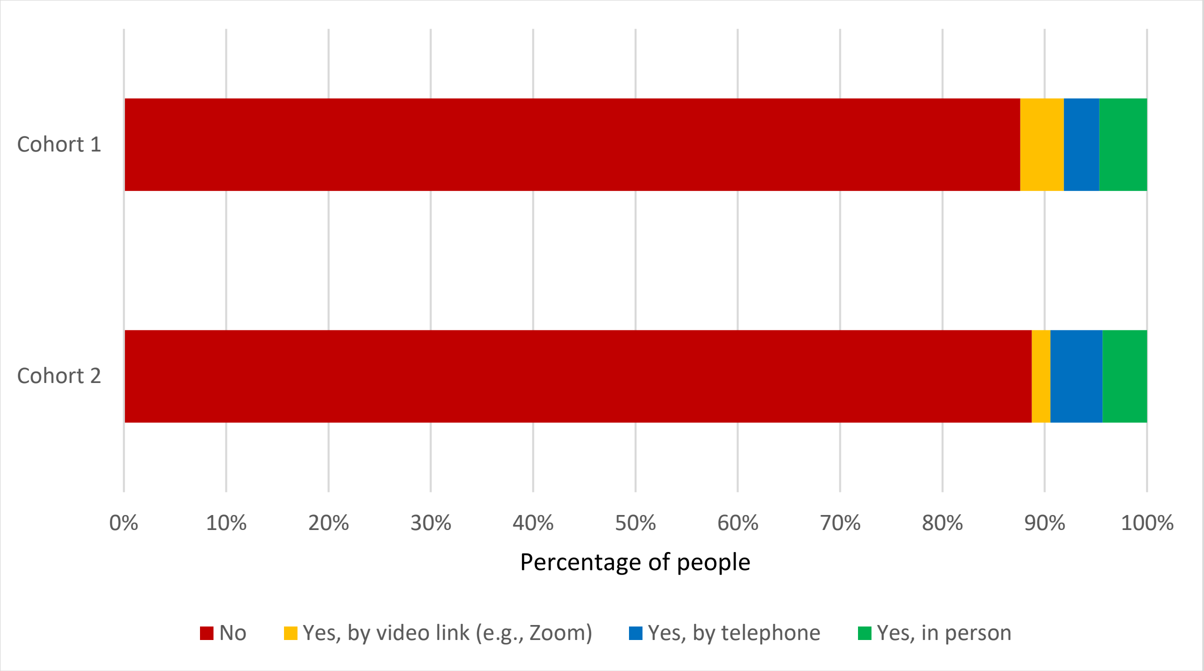

Figure 2.17. In the last four weeks have you/the person you support/care for been in contact with a Psychiatrist, Clinical Psychologist or Counsellor?

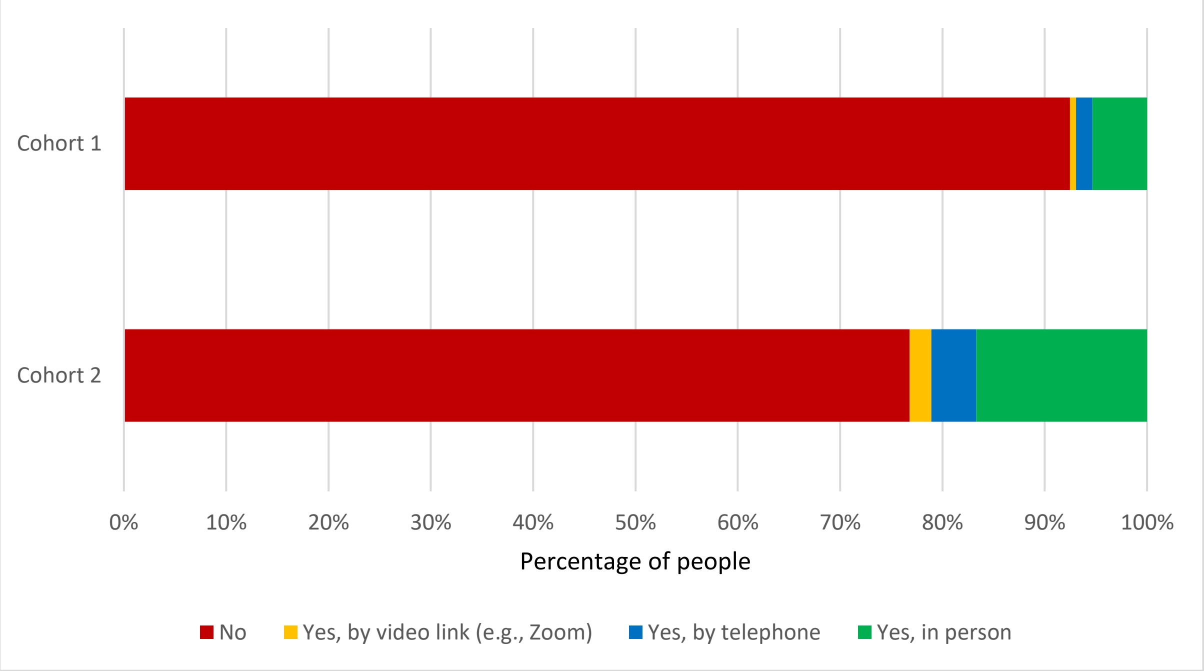

Figure 2.18. In the last four weeks have you/the person you support/care for been in contact with a speech and language therapist, occupational therapist, or physiotherapist?

In all four instances, and across both cohorts, over 64% of people with learning disabilities had not seen healthcare professionals in the last four weeks.

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 in the last four weeks. These data are presented in Table 2.9 for both cohorts.

Table 2.9. People with learning disabilities who had planned medical tests, operations or appointments cancelled in the last four weeks

	Cohort 1	Cohort 2
Planned medical test cancelled		
Yes	2%	9%
No	98%	88%
Don’t know		3%
Planned medical operation cancelled		
Yes	<1%	1%
No	100%	99%
Don’t know		0%
Planned hospital appointment cancelled		
Yes	3%	10%
No	97%	86%
Don’t know		4%

A higher percentage of people with learning disabilities in Cohort 2 were reported to have had a medical test (9%), operation (1%), or hospital appointment (10%) cancelled in the last week than in Cohort 1 (2%, <1%, and 3% respectively).

We asked follow-up questions about whether people with learning disabilities were currently waiting for planned medical tests, operations and hospital appointments. These data, and information about how long they had been waiting is displayed in Table 2.10.

Table 2.10. People with learning disabilities who were waiting for a planned medical test

	Cohort 1	Cohort 2
Are they waiting for a planned medical test?		
Yes	11%	24%
No	89%	73%
Don't know		3%
Of those waiting, how long have they been waiting for this planned medical test?		
Less than a month	22%	14%
1-2 months	30%	15%
3-6 months	9%	24%
More than 6 months	39%	47%
Are they waiting for a planned medical operation?		
Yes	6%	7%
No	94%	92%
Don't know		<1%
Of those waiting, how long have they been waiting for this planned medical operation?		
Less than a month	26%	15%
1-2 months	11%	10%
3-6 months	7%	25%
More than 6 months	56%	50%
Are they waiting for a planned hospital appointment?		
Yes	13%	32%
No	87%	65%
Don't know		3%
Of those waiting, how long have they been waiting for this planned hospital appointment?		
Less than a month	26%	14%
1-2 months	8%	17%
3-6 months	16%	25%
More than 6 months	50%	44%

More people with learning disabilities in Cohort 2 were waiting for a planned medical test (24%), operation (7%), or a hospital appointment (32%) than in Cohort 1 (11%, 6%, and 13% respectively). A large proportion of people with learning disabilities in both cohorts (>39%) had been waiting for more than 6 months for their medical test, operation, or hospital appointment.

2.3.4. Annual health checks

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). Further information about annual health checks is presented in Figure 2.19 for Cohort 1 and Figure 2.20 for Cohort 2.

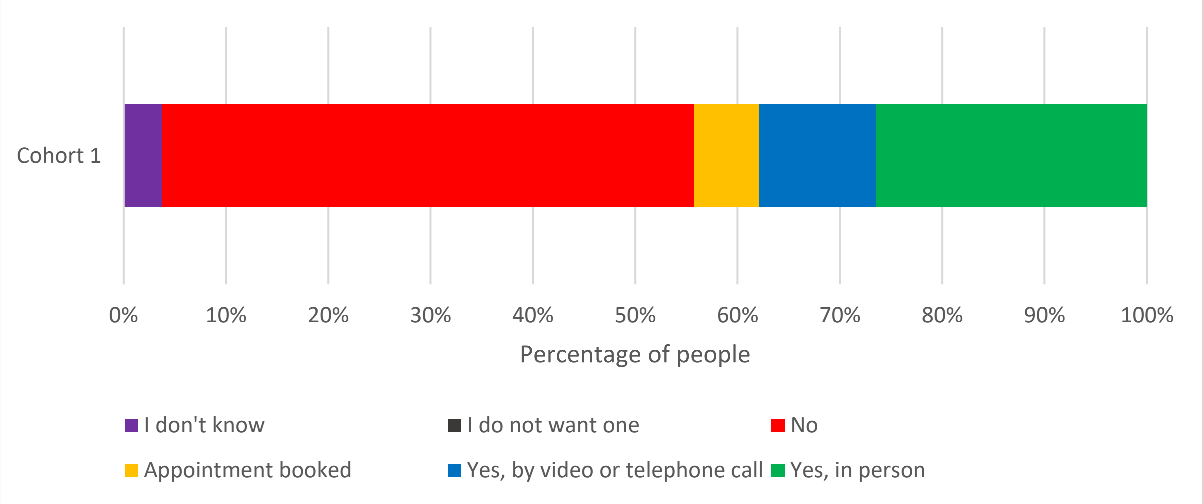

Figure 2.19. Since the start of this year (2021), have you had your annual health check? (Cohort 1 only, limited to only the 318 people who usually have an annual health check)

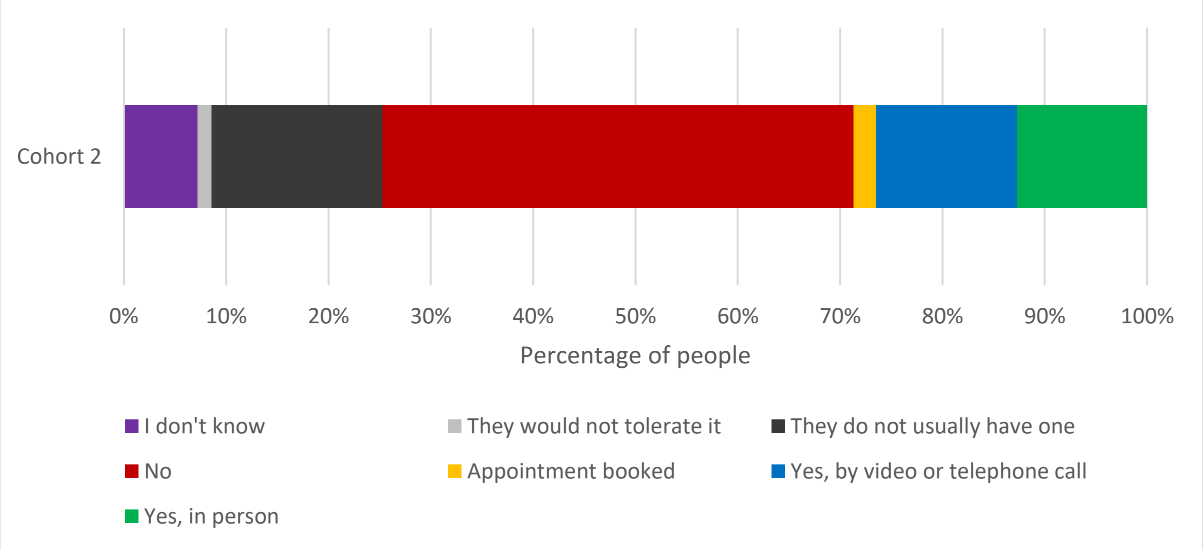

Figure 2.20. Since the start of this year (2021), has the person you support/care for had their annual health check? (Cohort 2 only)

Of the 318 people with learning disabilities in Cohort 1 who usually have an annual health check, only 27% had had them. This is a similar picture in Cohort 2, where only 27% of people with learning disabilities were reported to have had their annual health check in 2021, although 17% of people did not usually have one.

2.4. 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 3, which we will report on separately to explore changes over time.

We asked participants in Cohort 1 about their COVID-19-related worries in the week before the interview or survey, using an adapted version of the Pandemic Anxiety Scale[11]. Data related to all seven items in this scale are displayed in Figure 2.21.

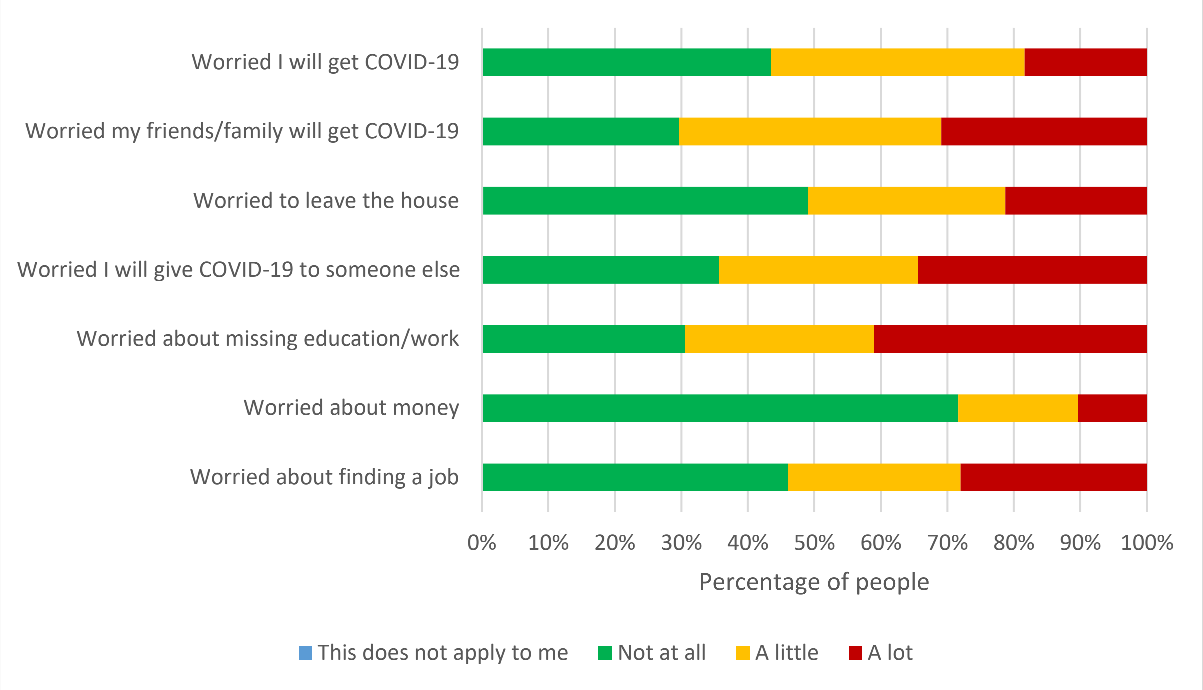

Figure 2.21. Questions on the Pandemic Anxiety Scale (Elroy et al., 2020) (Cohort 1 only)

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, 70% of participants showed at least a little concern that their friends/family will get COVID-19, 31% were very concerned. Half (50%) of the participants in Cohort 1 were at least a little worried to leave the house.

We also asked some general questions about the wellbeing of people with learning disabilities in both cohorts in the last four weeks, and these data are presented in Figures 2.22 and 2.23.

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[11] 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.

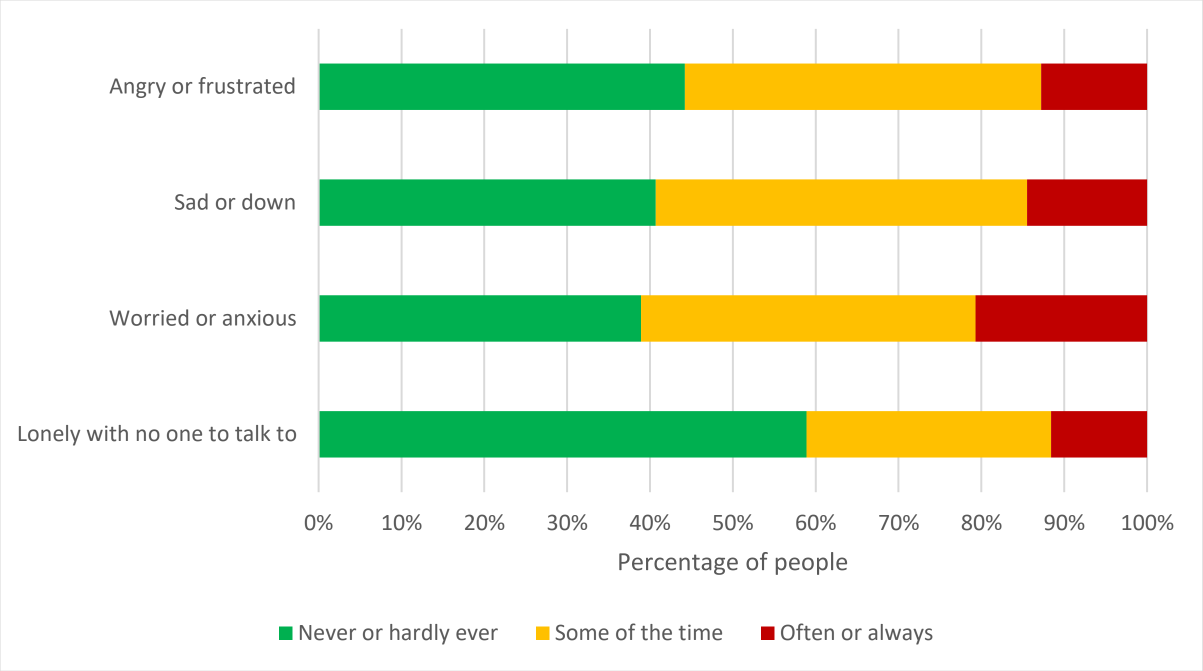

Figure 2.22. How people with learning disabilities have felt over the last four weeks (Cohort 1 only)

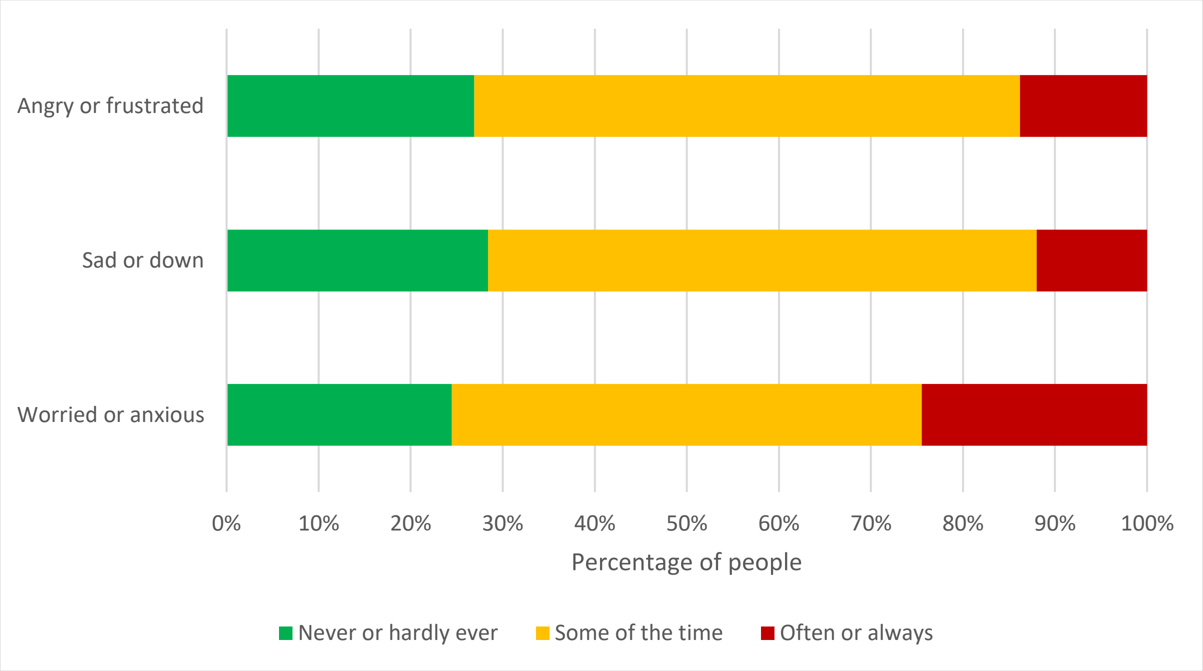

Figure 2.23. How people with learning disabilities have felt in the last four weeks (Cohort 2 only)

Most participants in Cohort 1 (>59%) reported 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. Similarly, over 72% of participants in Cohort 2 reported that the person they support/care for had felt angry or frustrated, sad or down, and worried or anxious at least some of the time in the last four weeks. In Cohort 1, 41% of participants said that they had felt lonely with no one to talk to at least some of the time in the last four weeks.

In both cohorts, we asked if people with learning disabilities were receiving any support when they are feeling sad, worried, or angry. These data are displayed in Table 2.11 below.

Table 2.11. Support for people with learning disabilities when they are feeling sad, worried or angry (Select all that apply)

	Cohort 1	**Cohort 2**
Yes, from a mental health professional	8%	9%
Yes, from someone paid to support them	35%	33%
Yes, from family	44%	60%
Yes, from friends	24%	8%
Yes, from mental health resources (online, videos, information, etc.)	3%	2%
Have not been sad, worried, or angry	20%	
Did not seek or get help	11%	
Not applicable		20%
Don’t know	1%	2%
Prefer not to say	0%	<1%

The majority of people with learning disabilities in both cohorts were receiving some support when they were feeling sad, worried, or angry. For people in Cohort 1, the most frequently reported sources of support were family (44%), paid support staff (35%), and friends (24%). In Cohort 2, the most frequently reported sources of support were family (60%), paid support staff (33%), and mental health professionals (9%).

2.5. 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,
- how people with learning disabilities are getting on with the people they live with,
- whether there are visitor restrictions where the people with learning disabilities live,
- whether people with learning disabilities knew people who had died during the COVID-19 pandemic, and
- how people are using technology (digital inclusion).

2.5.1. 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 2.24 below.

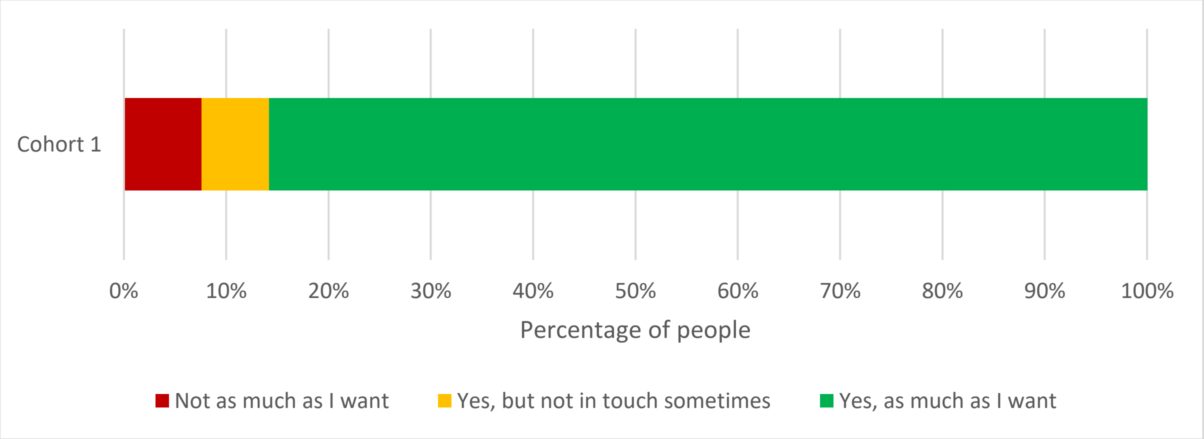

Figure 2.24. In the last four weeks have you been able to stay in touch with family and friends as much as you want? (Cohort 1 only)

Most people with learning disabilities in Cohort 1 reported that they were staying in touch as much as they wanted (86%), with 8% 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 in the last four weeks. 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 have stayed in contact with friends, family and other people in the last four weeks (Cohort 2 only)

		Cohort 2
Face-to-face		
	Yes	74%
	No	23%
	Don’t know	3%
Meet outside		
	Yes	68%
	No	29%
	Don’t know	3%
Meet in others’ house		
	Yes	30%
	No	69%
	Don’t know	1%
Meet in own house		
	Yes	52%
	No	45%
	Don’t know	3%
Meet in other indoor places		
	Yes	44%
	No	52%
	Don’t know	4%
Talk on telephone		
	Yes	46%
	No	54%
	Don’t know	<1%
Through video calls		
	Yes	54%
	No	44%
	Don’t know	3%
Other ways (e.g., photo albums or virtual hugs)		
	Yes	23%
	No	71%
	Don’t know	6%

The most frequently reported ways of staying in contact with family and friends were face-to-face (74%), meeting outside (68%), and through video calls (54%).

2.5.2. 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 2.25 presents the data from these questions.

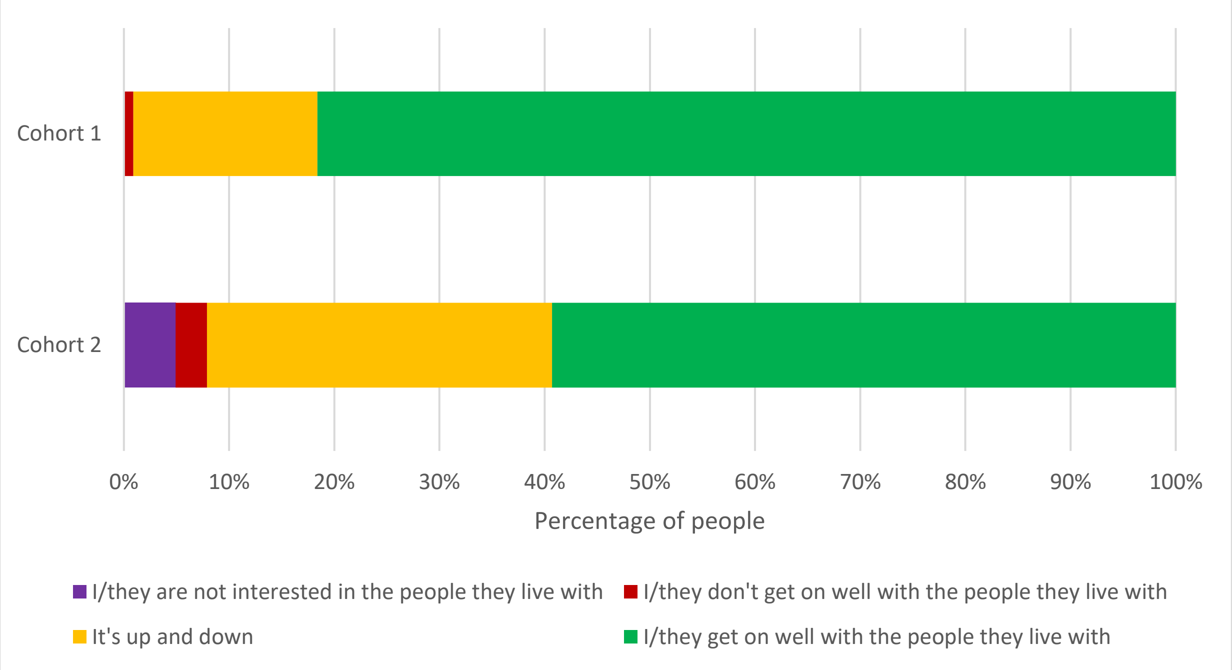

Figure 2.25. How people with learning disabilities have been getting on with the people they live with over the last four weeks

In both cohorts people with learning disabilities generally got on well with the people they lived with (>59%). 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 (82%). 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.

2.5.3. Visitor restrictions

Participants in both cohorts were asked about whether there had been any visitor restrictions in the last four weeks where the person with learning disabilities lived. For Cohort 1, we only asked people who lived in services about whether their service had stopped their friends and family visiting them. For Cohort 2, as the question asked was slightly different, we have separated these into two groups: people who live with family, and people who live in other places. These data are presented in Figures 2.26 and 2.27 below.

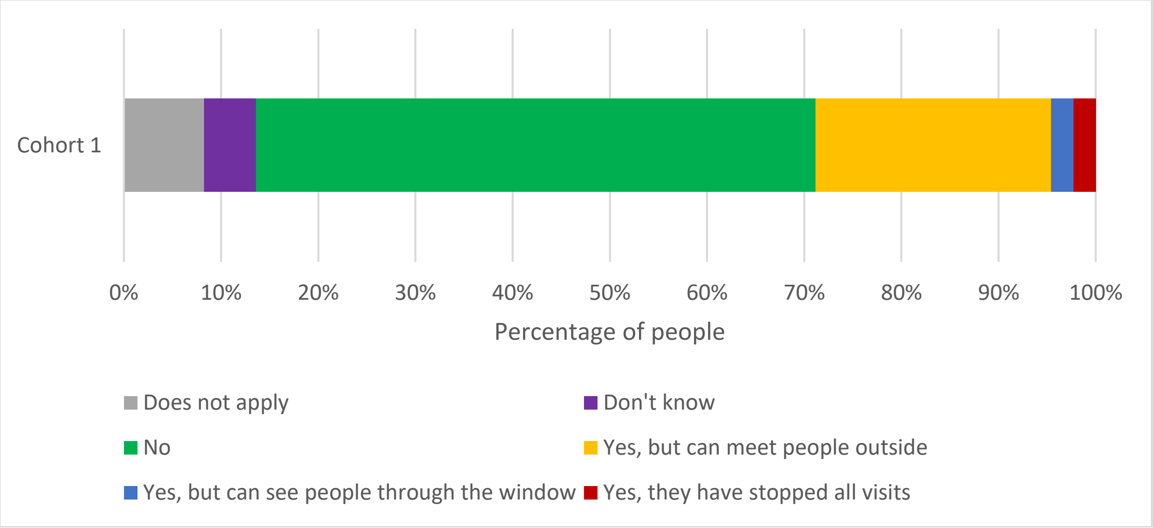

Figure 2.26 Has your service stopped your family or friends visiting you in your home over the last four weeks? (Cohort 1 only)

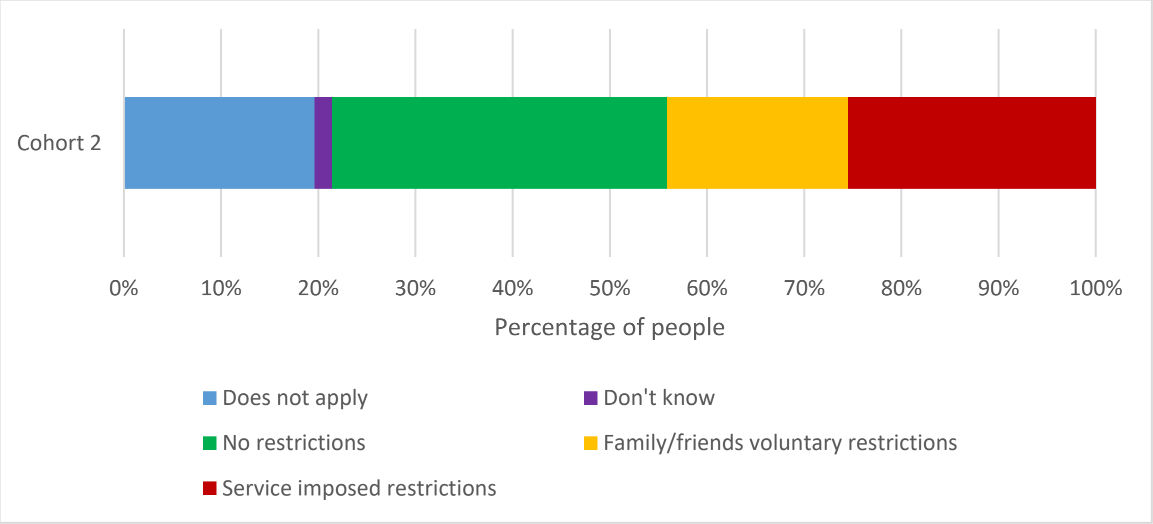

Figure 2.27. Have there been visitor restrictions to the home of the person you support/care for in the last four weeks? (Cohort 2 only)

In Cohort 1, 29% of people with learning disabilities had some form of visitor restrictions in their home that were imposed by their service. The most commonly reported type of restrictions were that there were restrictions, but they could still meet people outside (24%).

In Cohort 2, over 44% of people with learning disabilities had some form of visitor restrictions where they lived. Restrictions on visitors were typically imposed by the service provider (25%).

We asked participants in both cohorts some follow-up questions about visitor restrictions, including the extent of restrictions for family and friends, and whether they had been restricted in terms of when they could leave their home. These data are presented in Table 2.13. For the question about service restrictions on when people with learning disabilities could leave home, this was only asked of people who lived in services in both cohorts. The question about restrictions on visits from family and friends for Cohort 2 only was asked of all participants, regardless of living situation.

Table 2.13. Visitor restrictions for people with learning disabilities in the last four weeks

	Cohort 1	Cohort 2
Service restriction on when they can leave home		
Yes – cannot leave home at all	3%	2%
Yes – have to self-isolate for at least 7 days after leaving home	<1%	2%
Yes – cannot stay overnight with family or friends	3%	7%
No	77%	52%
Don't know	8%	2%
Does not apply	9%	36%
Restrictions on visits from family and friends		
Full access		49%
Restrictions on some occasions		12%
Partial access		22%
Only family and friends who are Key Workers		6%
No access		5%
Don't know		6%

In Cohort 1, 6% people with learning disabilities had some form of restrictions imposed on them about when they were able to leave their home. In Cohort 2, 11% people with learning disabilities had some form of restrictions imposed on them about when they were able to leave their home.

Almost half (49%) of people with learning disabilities in Cohort 2 had no restrictions on visits from family and friends. Almost a quarter (22%) had partial access, and 5% still had no access for family and friends.

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 2.28.

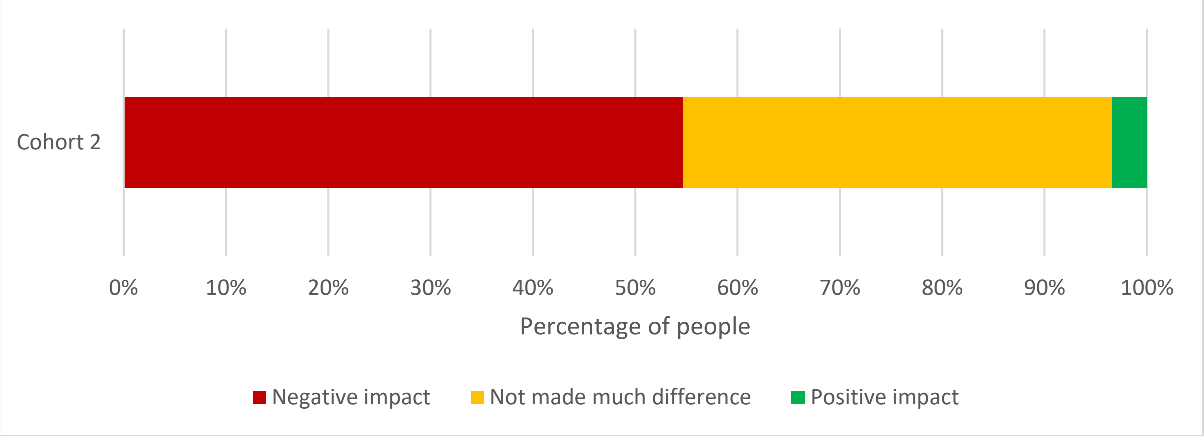

Figure 2.28. Have these restrictions on access/visits had an impact on the person you support/care for? (Cohort 2 only)

In Cohort 2, 55% of people with learning disabilities 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 2.3.

“After she stayed overnight twice at her Mother's house, the service told my Mother that if my sister caught coronavirus and tested positive in the care of my Mother, then my sister would not be allowed back in her my sister's home. My Mother who is 82 would have to look after my sister. As a family we decided that this was not an option. The service agreed that if my sister came for day visits to my Mother then she would not have to be tested before she returned, therefore would not be banned from her own home. This has really upset my sister who really enjoys overnight visits and can no longer have them.”

“As our son lives with and us supported by family no negative impact if visitor restrictions.”

“Client not allowed to touch and he is very tactile.”

“Coming from a large family it has meant that not everyone has been able to visit the person I support but they have agreed between themselves who should have priority contact.”

“He does not understand why we can’t go inside his home and as often as we did. This has made him withdrawn and reluctant to do much.”

“Likely wouldn't have had visitors anyway as visitors are very rare.”

“Sad lonely and isolating.”

“The person I care for only had one living family member who died during the pandemic and as a result has no visitors.”

“We can't have visitors at home, too risky, my son is having major anxiety and anger outbursts.”

“She previously went to a day centre every day and came home every weekend. She has been unable to do any of this since lockdown at the beginning of March 2020. She has been incredibly patient but of course her behaviour has deteriorated from time to time. Her mobility is deteriorating and she has had several UTIs. The nurse has noticed hand shaking and will follow up with the GP. She has several eye infections. My parents are desperately impacted by this. They are 90 and 83 and missing her desperately.”

Box 2.3. Please describe the impact of visitor restrictions on the person you support/care for (Cohort 2 only)

The impact of visitor restrictions varied, with some participants in Cohort 2 reporting that the person they support/care for did not see any negative effects of restrictions, or was living at home without restrictions. Some commonly reported negative impacts were social isolation, loneliness, behavioural and health-related deteriorations, and family missing their loved ones.

2.5.4. Deaths during the COVID-19 pandemic

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 during the COVID-19 pandemic from any cause, including COVID-19. These data are displayed in Figures 2.29 and 2.30.

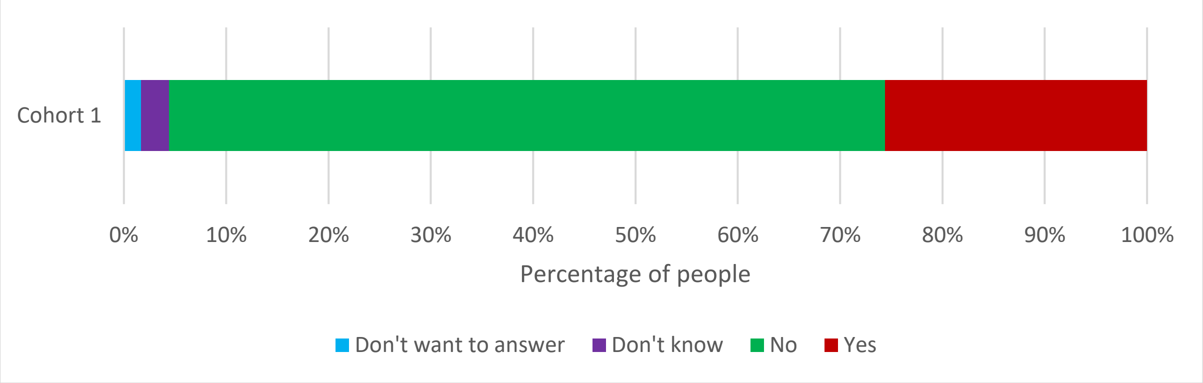

Figure 2.29. Has anyone you knew well or someone important to you died from any illness or any reason at all since the beginning of the COVID-19 pandemic? (Cohort 1 only)

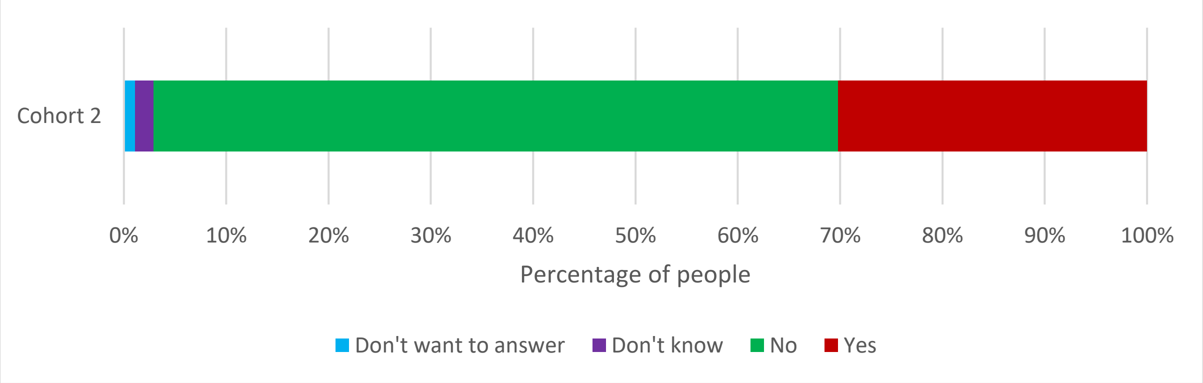

Figure 2.30. Has anyone the person you support/care for knew well or someone important to them died from any illness or any reason at all since the beginning of the COVID-19 pandemic? (Cohort 2 only)

From these two figures, we can see that number of people with learning disabilities in both Cohort 1 and Cohort 2 (N = 124 and 84 respectively) have experienced someone close to them die during the COVID-19 pandemic, with this proportion being largest for Cohort 2 (30% vs 26% in Cohort 1).

In this Wave of the study, of all the people who had experienced someone close to them die, we asked follow-up questions about the number of people who had died, and what their relationships were to the people with learning disabilities in both cohorts. These data are presented in Table 2.14 and Figure 2.31.

Table 2.14. Of the people with learning disabilities who have had someone who was known well or important to them die since the start of the COVID-19 pandemic, how many people have died?

	Cohort 1 (n = 124)	Cohort 2 (n = 84)
One	75%	54%
2-3	22%	43%
Four or more	3%	3%

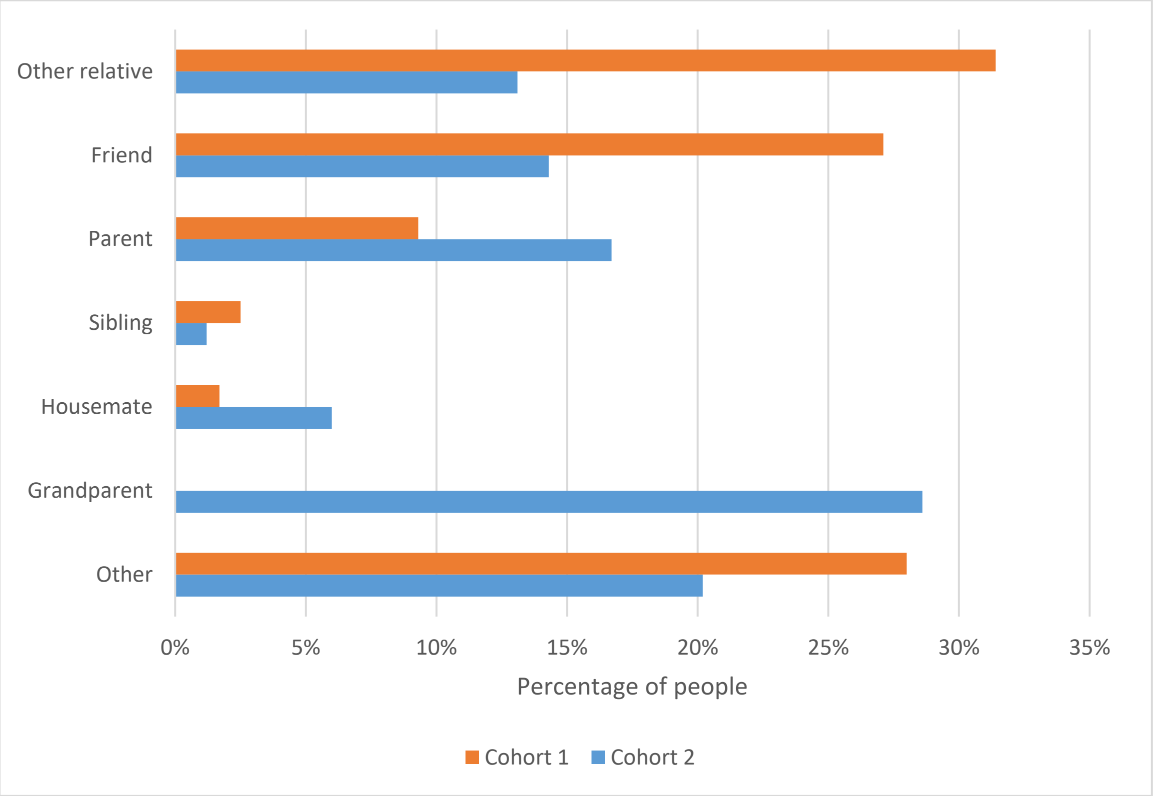

Figure 2.31. Relationship to the person who was most important to them who died during the COVID-19 pandemic (Select one only) (Cohort 1: n = 124; Cohort 2: n = 84)

In Cohort 1, of the 124 people who reported that someone close to them had died, the most frequently reported relationship to an important person who had died during the COVID-19 pandemic was a relative other than a parent, child, sibling, partner/spouse (e.g., a grandparent) (31%). In Cohort 2, of the 84 people who were reported to have had someone close to them die, this was most frequently reported to be a grandparent (29%). When asked about how much they thought that their life had changed because those important people had died, people in Cohort 1 most frequently reported that they felt that their life hasn’t changed much (36%). In Cohort 2, family carers/paid support staff reported that their life hasn’t changed much (54%).

We asked if there was anyone who people with learning disabilities could talk to about what the death of the people who were important to them had been like for them, and these data are presented in Table 2.15.

Table 2.15. Are there people you/they can talk with about what this has been like for you/them?

	Cohort 1 (n = 124)	Cohort 2 (n = 84)
A counsellor is helping	4%	1%
A health professional (e.g., a psychologist, community nurse) is helping them	5%	2%
The people around them are helping them	80%	45%
There is no one to help them	<1%	14%
They don't need that kind of support	9%	37%

The majority of people with learning disabilities in both cohorts had someone to talk to about what the death of important people had been like for them. In both cohorts, this was most frequently reported as being the people around them (80% and 45% respectively). More people in Cohort 2 than in Cohort 1 were reported to have no one to help them (14% vs. <1% respectively), and to not need that kind of support (37% vs. 9% respectively).

2.5.5. 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 2.16 below.

Table 2.16. Internet and telephone access and use for people with learning disabilities

	Cohort 1	Cohort 2
Uses Internet at Home		
Yes	92%	
Has internet but doesn't use	4%	
Doesn't have the internet	4%	
Has a telephone that they can make calls on		
Yes	97%	
No	3%	
Access to internet/telephone		
Internet at home		74%
Device to use internet without support		16%
Device to use internet with support		21%
Telephone for calls		36%
Telephone to be used on their behalf		31%
Internet to be used on their behalf		23%

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 under half of participants (37%) reported that the person they support/care for had a device that they could use the internet on, with or without support. In Cohort 1, 97% of people had a telephone that they could make calls on, and in Cohort 2, 67% of people had access to a telephone that they could use or could be used on their behalf to make calls.

We also asked about what people who had the internet where they lived used it for during the data collection period (July-August 2021), and how long they usually spend on the internet for non-work-related activities. These data are displayed in Figures 2.32 and 2.33 below.

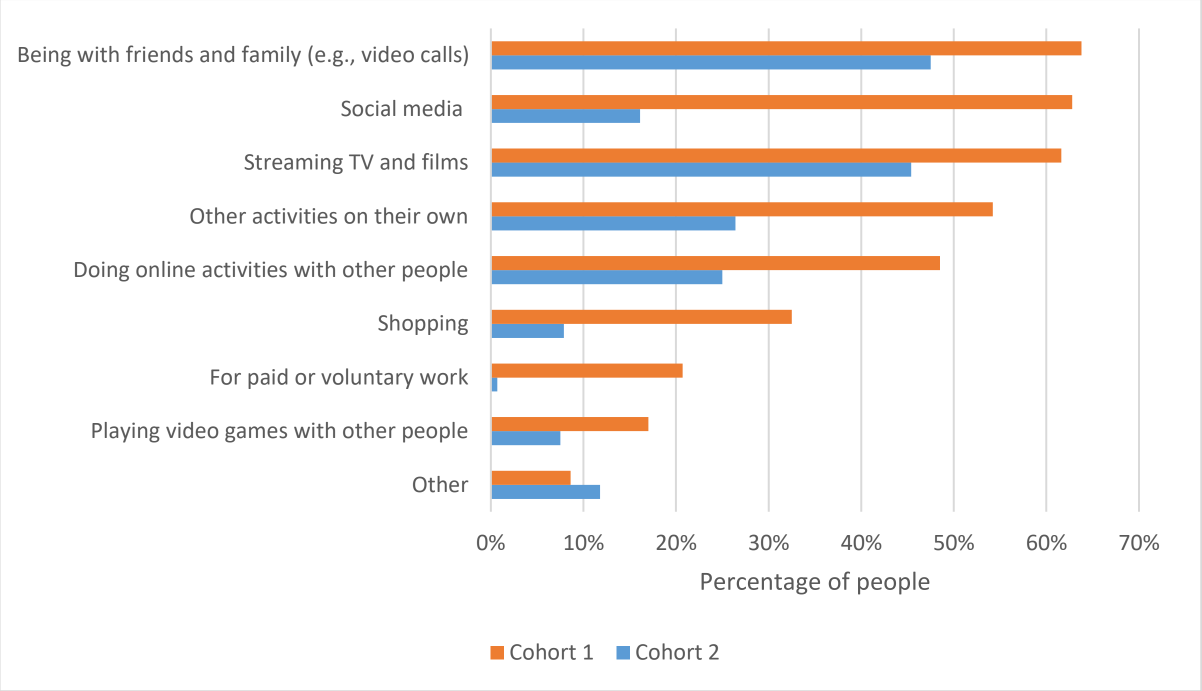

Figure 2.32. What people with learning disabilities currently use the internet for

The most common uses for the internet for people with learning disabilities in Cohort 1 were being with friends and family (e.g., video calls), going on social media, and streaming television programmes and films. In Cohort 2, the most common uses for the internet for people with learning disabilities were being with friends and family (e.g., video calls), streaming television and films, and doing online activities on their own. In Cohort 1, 101 people with learning disabilities (21%) were using the internet for work or volunteering. In Cohort 2, two people with learning disabilities (<1%) were using the internet for work or volunteering.

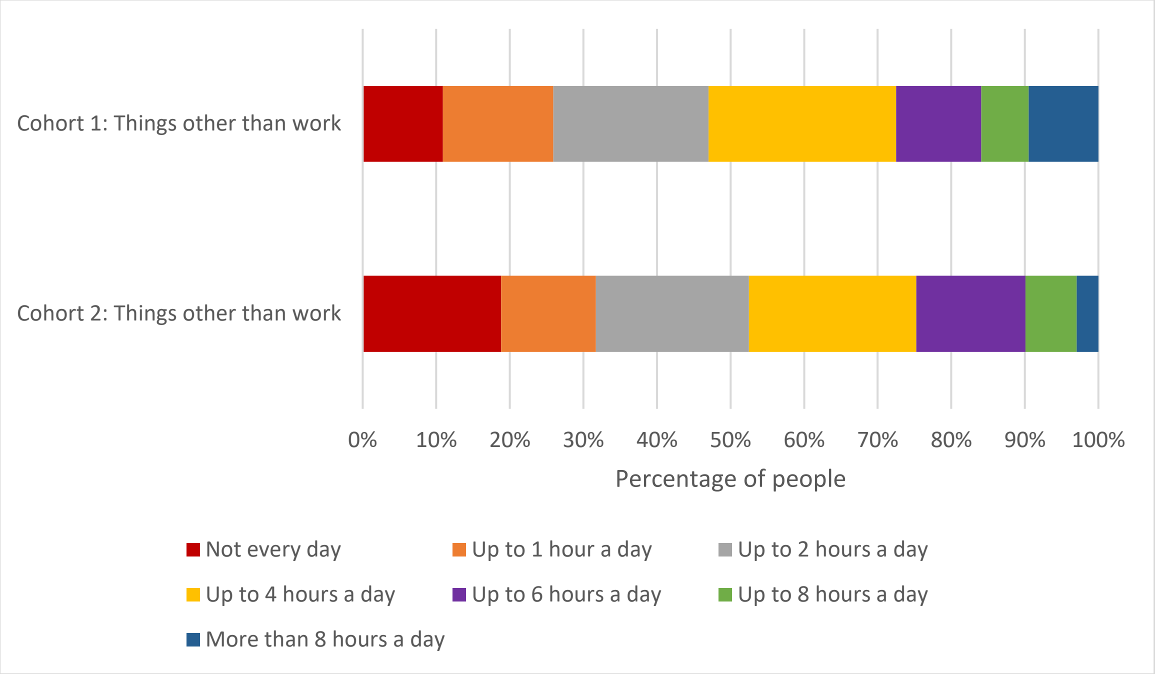

Figure 2.33. How long people with learning disabilities who used the internet would use it for each day for non-work purposes

As can be seen in Figure 2.33, 53% of people in Cohort 1 and 48% of people in Cohort 2 used the internet for more than two hours per day.

Figures 2.34 and 2.35, below, show how people with learning disabilities in both cohorts felt about taking part in online activities.

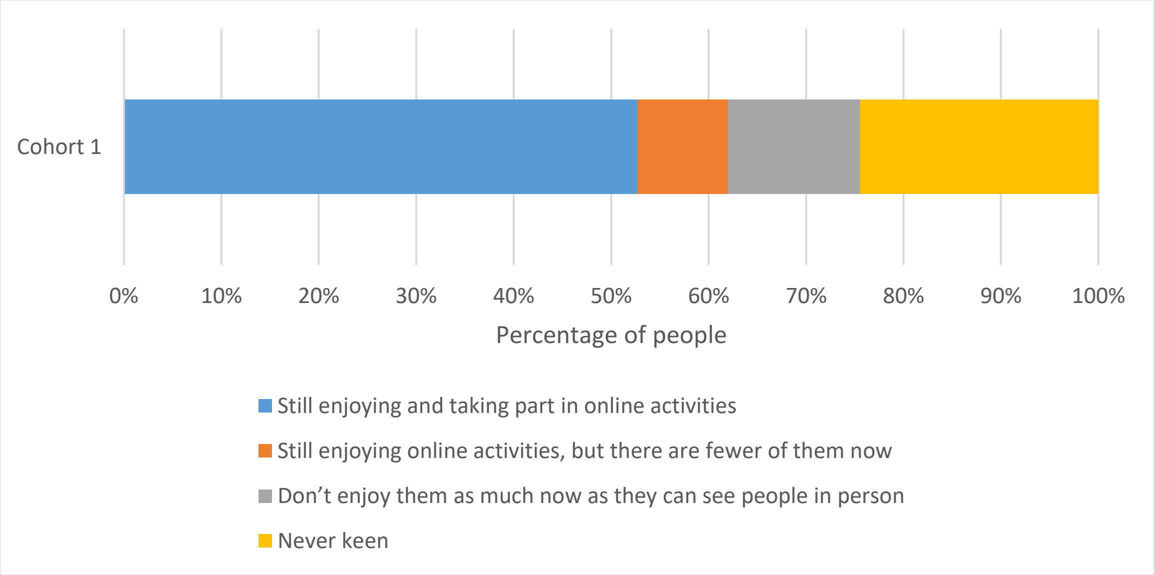

Figure 2.34. In the last four weeks, how keen have you been to take part in online activities? (Cohort 1 only)

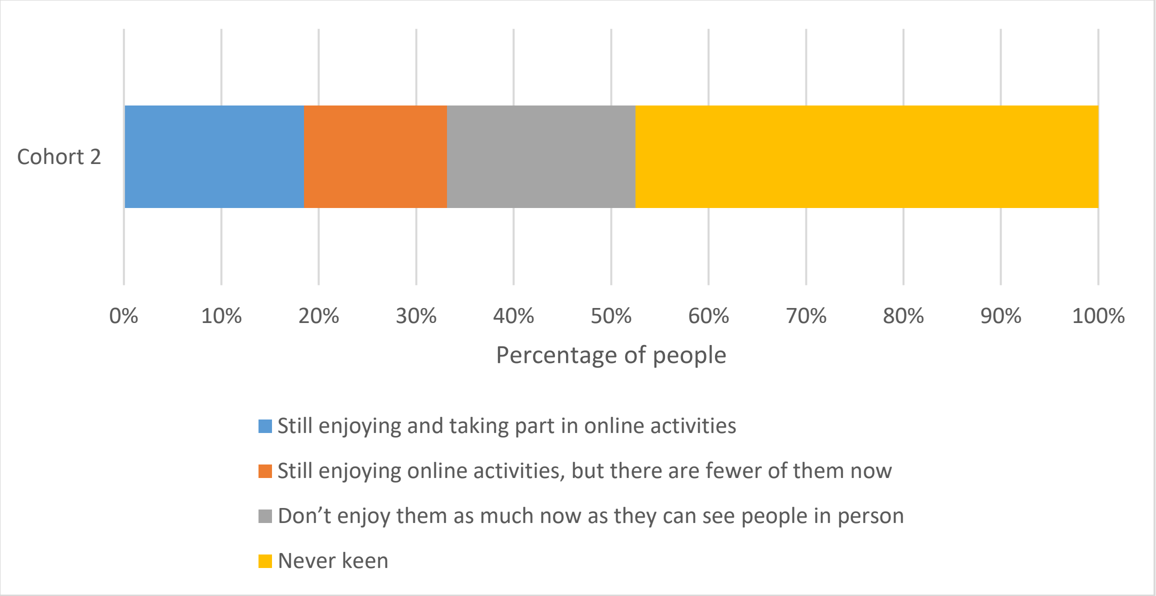

Figure 2.35. Since the early days of the pandemic in 2020, how keen has the person you support/care for been to join online activities? (Cohort 2 only)

In Cohort 1, the majority of people with learning disabilities (53%) reported that they are still enjoying and taking part in online activities. In Cohort 2, 48% of people with learning disabilities were never keen to join online activities, and 19% don’t enjoy them as much now that they can see people in person. Overall, 33% were still enjoying online activities.

2.6 Sources of support

In this sub-section, we report on questions about formal sources of support, including:

- access to formal sources of support,
- changes to support,
- satisfaction with support, and
- personal budgets.

2.6.1. Access to support

Figure 2.36 and Table 2.17 present data about whether people with learning disabilities had received formal sources of support in the four weeks before the interview or survey.

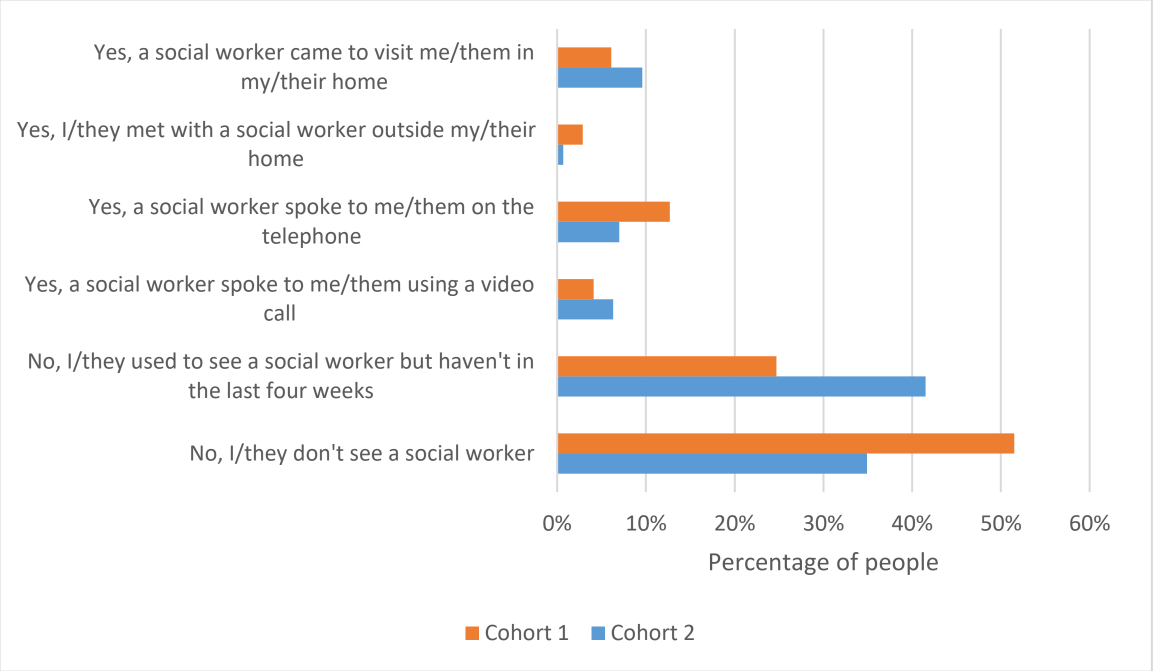

Figure 2.36. Contact with social workers in the last four weeks for people with learning disabilities (Select all that apply)

Overall, 24% of people with learning disabilities in Cohort 1 had had some contact with their social worker in the last four weeks. This was most commonly reported as being by telephone (13%). In Cohort 2, overall, 24% of people with learning disabilities had had some contact with their social worker in the last four weeks. This was most commonly reported as being visited in their own home (10%).

Table 2.17. Use of formal supports in the last four weeks

	Cohort 1	Cohort 2
Day service		
Yes, outside the home	20%	29%
Yes, online activities at home	2%	<1%
Yes, a combination of activities outside the home and online	2%	4%
No, do not use a day service	67%	46%
No, day service is not open	7%	12%
No, day service is open but cannot/does not want to use it at the moment	3%	8%
Community activities (e.g., pub, cinema, clubs)		
Yes, outside the home	29%	26%
Yes, online activities at home	11%	6%
Yes, a combination of activities outside the home and online	16%	10%
No	43%	58%
Further education		
Yes, outside the home	2%	4%
Yes, online activities at home	2%	<1%
Yes, a combination of activities outside the home and online	<1%	1%
No, should be attending but have not in the last four weeks	5%	10%
Does not attend Further Education	91%	84%
Personal assistants/support workers helping at home		
Yes	51%	57%
No	2%	0%
They do not get this service	47%	37%
Used to have personal assistants/support workers, but not in the last four weeks		6%
Going out with personal assistants/support workers		
Yes	49%	63%
No	4%	0%
They do not get this service	48%	26%
Used to have personal assistants/support workers, but not in the last four weeks		11%
Online activities arranged by self-advocacy groups		
Yes	40%	14%
No	60%	86%
Short breaks/respite services		
Yes	18%	14%
No	83%	86%

Overall, 24% of people with learning disabilities in Cohort 1, and 33% of people with learning disabilities in Cohort 2 had attended day services in the last four weeks (either online or face-to-face). This was more frequently reported as being face-to-face. For community activities, 56% of people with learning disabilities in Cohort 1, and 42% of people with learning disabilities in Cohort 2 were reported to have accessed these in some form over the last four weeks. Generally, people with learning disabilities were more frequently reported to be attending face-to-face community activities.

In Cohort 1, people were often reported to be receiving formal support from personal assistants inside their home, and in the community (51% and 49% respectively). In Cohort 2, it was 57% and 63% respectively.

In both cohorts, people were most frequently reported to not be accessing activities arranged by self-advocacy groups (60% and 86% respectively). For short breaks and respite services, 18% of people with learning disabilities in Cohort 1 and 14% of people with learning disabilities in Cohort 2 were reported to have received these in the last four weeks.

We also asked participants in both cohorts about how many days in the last four weeks they (Cohort 1), or the person they support/care for (Cohort 2), had been to day services, community activities, had personal assistants or support workers helping at home, or had been out with personal assistants or support workers, if they had accessed these formal supports. These data are displayed in Table 2.18.

Table 2.18. Number of days in the last four weeks that people with learning disabilities have accessed formal supports

	Cohort 1	Cohort 2
Day service		
More than five days a week	2%	20%
4-5 days a week	24%	22%
2-3 days a week	38%	24%
One day a week	27%	11%
2-3 days in the last four weeks	6%	15%
Only one day in the last four weeks	3%	10%
Community activities (e.g., pub, cinema, clubs)		
More than five days a week	7%	2%
4-5 days a week	19%	14%
2-3 days a week	30%	46%
One day a week	31%	13%
2-3 days in the last four weeks	15%	19%
Only one day in the last four weeks	8%	5%
Personal assistants/support workers helping at home		
More than five days a week	69%	55%
4-5 days a week	10%	15%
2-3 days a week	11%	14%
One day a week	9%	8%
2-3 days in the last four weeks	3%	5%
Only one day in the last four weeks	0%	3%
Going out with personal assistants/support workers		
More than five days a week	17%	20%
4-5 days a week	13%	22%
2-3 days a week	35%	24%
One day a week	23%	11%
2-3 days in the last four weeks	8%	15%
Only one day in the last four weeks	5%	10%

In both cohorts, people with learning disabilities were most frequently reported to access a day service between two and five days a week (62% and 46% respectively). More people in Cohort 2 were reported to access a day service more than five days a week than in Cohort 1 (20% and 2% respectively). For community activities, most people with learning disabilities in both cohorts were accessing these between one and three days a week (61% and 59% respectively). People with learning disabilities in both cohorts were most frequently reported to have help at home from personal assistants or support workers more than five days a week (69% and 55% respectively). The number of people who were reported to go out with personal assistants or support workers varied in both cohorts, with the most common frequency being two to three days a week for both cohorts (35% and 24% respectively).

2.6.2. Changes to and satisfaction with support

We also asked participants in both cohorts about any changes to support since before the COVID-19 pandemic. These data are displayed in Table 2.19.

Table 2.19. Changes to support since before the COVID-19 pandemic

	Cohort 1	Cohort 2
Support now vs. pre-pandemic		
More support now	11%	6%
About the same	47%	39%
Less support now	20%	48%
Does not get services	22%	7%
Going out to services and people supporting them now vs. pre-pandemic		
Go out for these more now	7%	3%
About the same	39%	21%
Go out for these less now	41%	54%
Does not apply	14%	21%
Online services/contact		
More online services/contact now	45%	23%
About the same	14%	18%
Less online services/contact now	6%	6%
Not offered online services/contact	28%	42%
Have refused online services/contact	7%	11%

Generally, people with learning disabilities in Cohort 1 (47%) were getting about the same support as they were before the pandemic. In Cohort 2, people with learning disabilities were reported to receive less support now (48%) They were going out less than they were before the pandemic (41% and 54% respectively). Finally, in Cohort 1 they were getting more online services/contact than they were before the pandemic (45%), but in Cohort 2 42% had not been offered online services/contact.

The next question was only asked of the 268 people in Cohort 1 who said that their services had changed, and the 192 of people in Cohort 2 who reported that the services of the person with learning disabilities who they cared for/supported had changed. When asked about whether they were asked if they wanted their services to change or were told how they were going to change, 19% of people with learning disabilities in Cohort 1 and 11% in Cohort 2 were reported to have been asked about the changes. These data are presented in more detail in Figure 2.37.

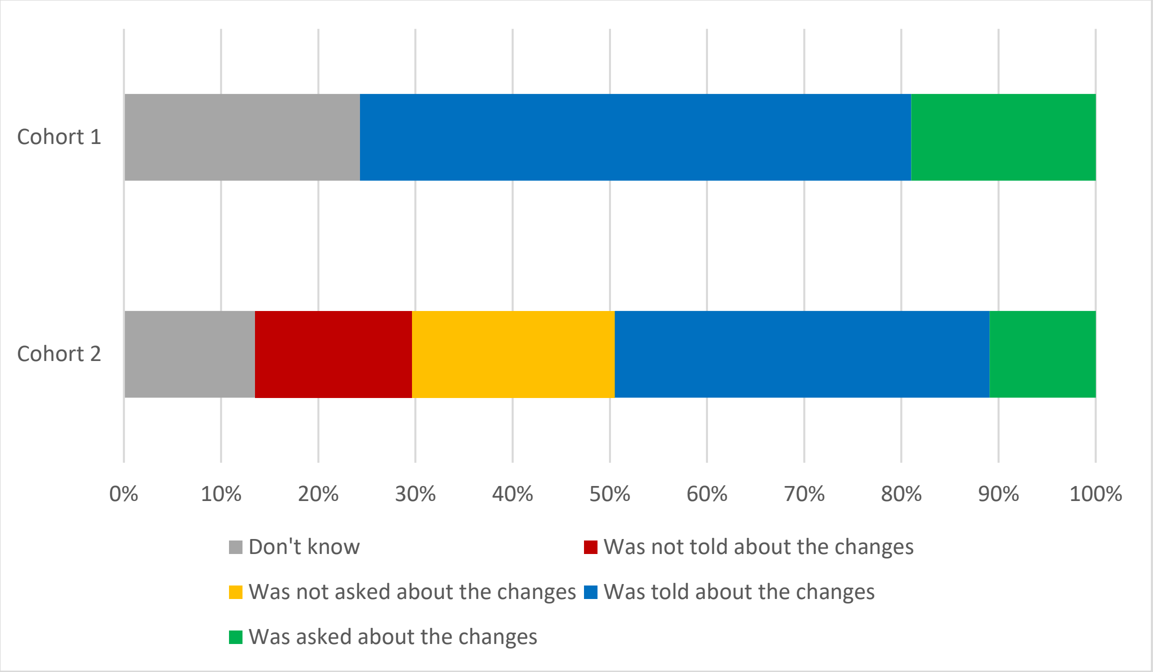

Figure 2.37. Were people with learning disabilities asked or told about service changes? (Sample: Cohort 1 (n=268), Cohort 2 (n=192))

The majority of people with learning disabilities in Cohort 1 whose services had changed (57%) reported that they had been told about the changes. Of the 51 people in Cohort 1 who were asked about what changes they wanted, 96% said that services listened to them. In Cohort 2, 39% of people with learning disabilities whose services had changed were reported to have been told about the changes. We also asked about whether people with learning disabilities were happy with the services and supports they have now, and these data are displayed in Figure 2.38.

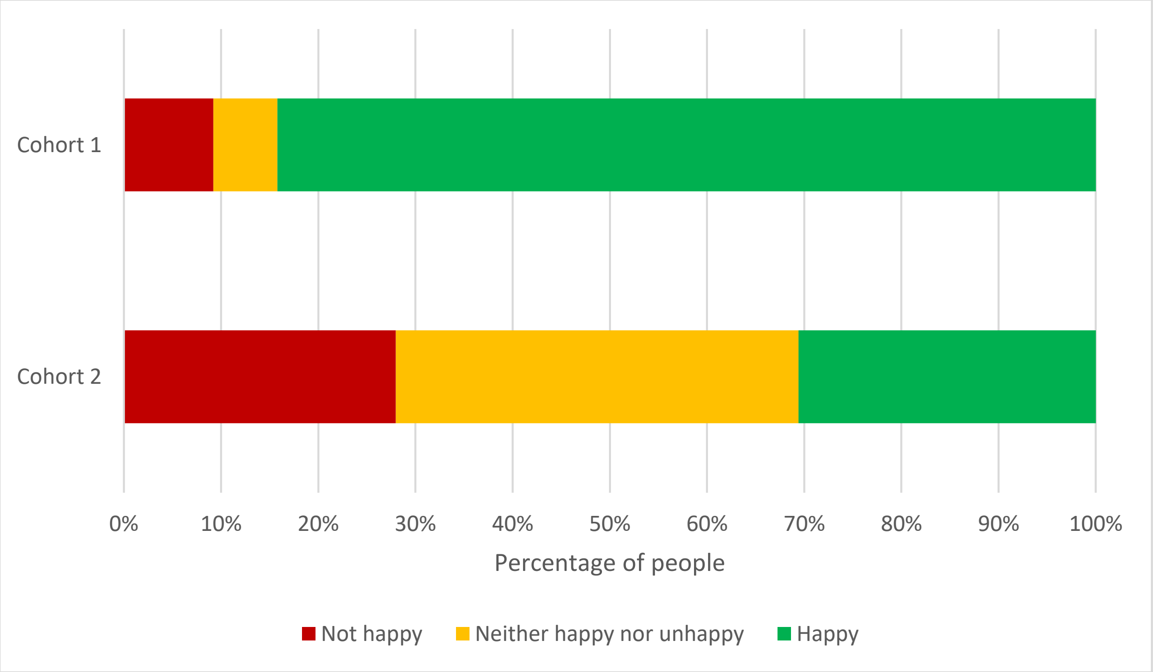

Figure 2.38. Are people with learning disabilities happy with the services and supports they have now?

The majority of people with learning disabilities in Cohort 1 (84%) were reported to be happy with their current services and supports. In Cohort 2, more participants reported that the person they support/care for was neither happy nor unhappy (42%), than either happy (31%) or unhappy (28%).

2.6.3. Personal budgets

In Cohort 1, 15% of people with learning disabilities reported that they knew roughly how much money they get for services and supports. In Cohort 2, 45% of family carers and paid support staff reported knowing roughly how much money the person they support/care for gets for services and supports. Some people with learning disabilities in both cohorts were not receiving any services (22% and 11% respectively). Further detail about personal budgets is presented in Figure 2.39 and Table 2.20 below.

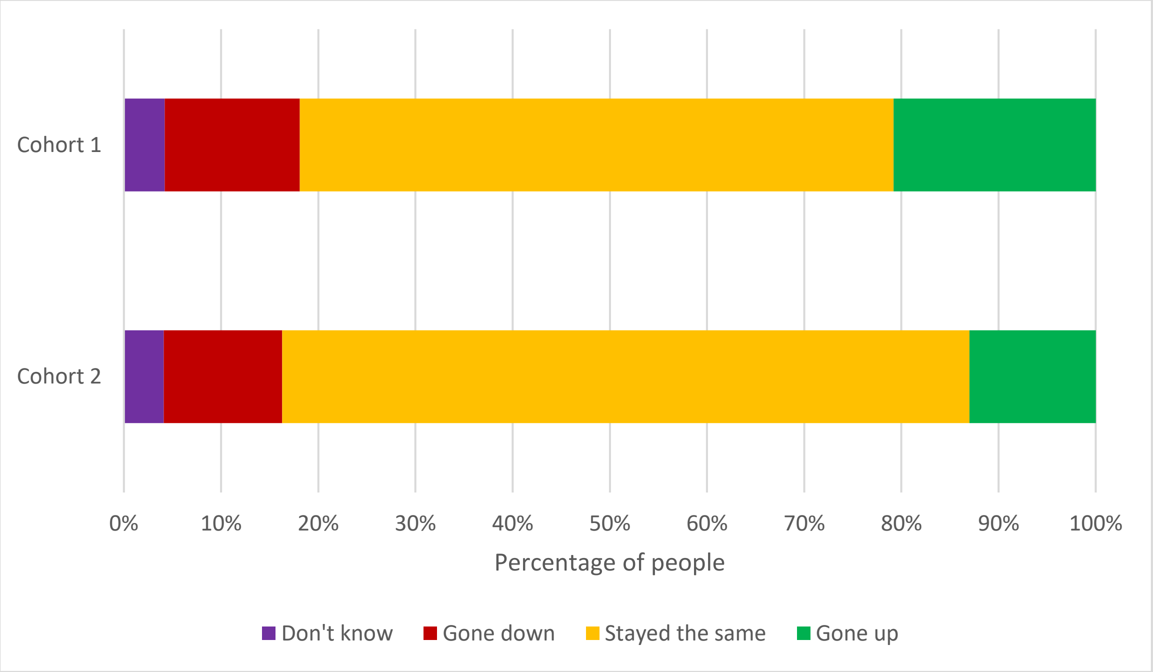

Figure 2.39. Changes in the amount of money received by people with learning disabilities for support and services in the last year

Most frequently, people with learning disabilities in both cohorts reported that the amount of the money they received had stayed the same in the last year (61% and 71% respectively).

Table 2.20. Money for services and supports for people with learning disabilities

		Cohort 1	Cohort 2
Money being used for services that are not currently being received			
	Yes	31%	39%
	No	60%	52%
	Don’t know	10%	9%
Services and supports have become more expensive			
	Yes	25%	29%
	No	49%	43%
	Don’t know	26%	28%
Person with learning disabilities or family members pay for services			
	Yes	36%	42%
	No	54%	48%
	Don’t know	10%	10%
Cut back services and supports because they can’t afford them			
	Yes	13%	
	No	78%	
	Don’t know	10%	

Participants in both cohorts reported they were paying for services they were not receiving (31% and 29% respectively). They also reported that their services and supports had not become more expensive (49% and 43% respectively) and they were not paying for services themselves (54% and 48% respectively). In Cohort 1, people with learning disabilities reported that they had not cut back services and supports because they can’t afford them (78%).

We also asked family carers and paid support staff in Cohort 2 about what the impact of reduced services and supports have been on the person they supported/cared for. Some of these comments are presented in Box 2.4.

“A severe decline in behaviour. Frequently walking around shouting and rocking. Sleep patterns completely disrupted and frequent bouts of bad temper and frustration. An almost complete unwillingness to cooperate with caters at home. High incidence of incontinence both at home and while travelling.”

“After so many months with nothing even this is an improvement and she is happy to be back to a part of what she was used to.”

“As a family we have worked round the clock to minimise a negative impact on our son. But we are absolutely exhausted now but as he is happy and healthy it is worth it.”

“Bored. Frustrated. Exhibited some violent behaviour. Forced to spend too much time with housemates he didn't choose. After some months became lethargic. Resigned to reduced life.”

“Currently going through transition from children to adult services. Already seeing changes in arranging respite etc.”

“Everything has changed and her mental health has suffered. She has stopped eating and now has supplements from the dietitian. She has lost almost 9 stone in a year.”

“Less contact with friends, gets bored at home and sometimes frustrated and is grumpier. They eat more out of boredom and have put on weight.”

“Made his dementia worse.”

“Much less social interaction. Individuals now have to organise themselves to meet with friends in public places. This is obviously more risky than meeting at day centres etc (which are closed as they are deemed risky!)”

“She is frustrated at lack of meaningful activity and is not allowed to go to a day service that she used to enjoy, even though it has been open since April.”

“Support staff have to prioritise clients needing 24/7 care; with many staff sick or self isolating, shift cover has been stretched very thin, & shifts cancelled.”

“The impact of not being out of the care home in nearly 18 months has resulted in mobility being reduced, deteriorating mental health, reduced quality of life.”

Box 2.4. What has been the impact of reduced services and supports on the person that you support? (Cohort 2 only)

Many participants in Cohort 2 reported that the reduction in services and supports for the person they support/care for has led to increases in behaviour that challenges, frustration, and isolation as well as reductions in mental and physical health. Some family carers reported that they are exhausted, because they are trying to keep the life of the person they support/care for as normal as possible. A minority of participants reported that services and supports had returned to some degree, which was an improvement on previous months.

2.7. 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,
- about the reasons why people with learning disabilities are leaving their homes,
- about the employment of people with learning disabilities,
- about the finances of people with learning disabilities, and
- about their neighbourhood.

2.7.1. Food

Participants in both cohorts answered questions about how people with learning disabilities were getting food at the minute. The data from these questions are presented in Table 2.21.

Table 2.21. How people with learning disabilities are getting food (Select all that apply)

	Cohort 1	**Cohort 2**
Shopping on their own	31%	
Shopping with support/care worker	28%	
Shopping with family	27%	
Through family	26%	59%
Shop online on their own	11%	
Through support/care workers	9%	
From support organisations	5%	
Someone else shops online for them	4%	
Click and Collect	1%	
Through friends or neighbours	1%	1%
From a food bank	1%	<1%
Finding it difficult to get food	<1%	<1%
Food parcels – they are shielding	0%	<1%
From the place they live in		21%
Shopping with support		17%
Delivered from supermarkets		13%
From other people		2%
Community support project		<1%

Our data indicate that less than 1% of people with learning disabilities in both cohorts were finding it difficult to get food. People with learning disabilities in Cohort 1 were most frequently reporting that they were going shopping on their own (31%). Participants in Cohort 2 reported that a large percentage of people with learning disabilities were getting food through family (59%). Very few people in either cohort (1% or less) were getting food from a food bank.

2.7.2. Medications

In Cohort 1, 77% of people with learning disabilities and in Cohort 2, 79% of people with learning disabilities were taking medications. Table 2.22 displays data about how people with learning disabilities in both cohorts were getting their medicines.

Table 2.22. Obtaining medicines (Select all that apply)

	Cohort 1 (n = 374)	**Cohort 2 (n = 216)**
On own – from pharmacy/chemist	21%	
From family	19%	40%
Delivered from pharmacy/chemist – organised by someone else	14%	
From support workers or support organisation	13%	
With support – from pharmacy/chemist	12%	11%
Delivered from pharmacy/chemist – order by telephone	8%	
Delivered from pharmacy/chemist – order online	3%	
From friends/neighbours	<1%	<1%
Finding it difficult	0%	0%
Not getting medicines	0%	0%
Delivered from pharmacy/chemist		16%
From the place they are living in		13%
Through a community support project		<1%

No one in either cohort was finding it difficult to get their medicines or were not getting medicines they needed. In both cohorts, it was relatively common for people with learning disabilities to receive medicines from family (Cohort 1 = 19%, Cohort 2 = 40%).

2.7.3. Leaving the house

We asked about the reasons people with learning disabilities left their home during the week before the interview or survey. The reasons people with learning disabilities in both cohorts left their houses are presented in Figure 2.40.

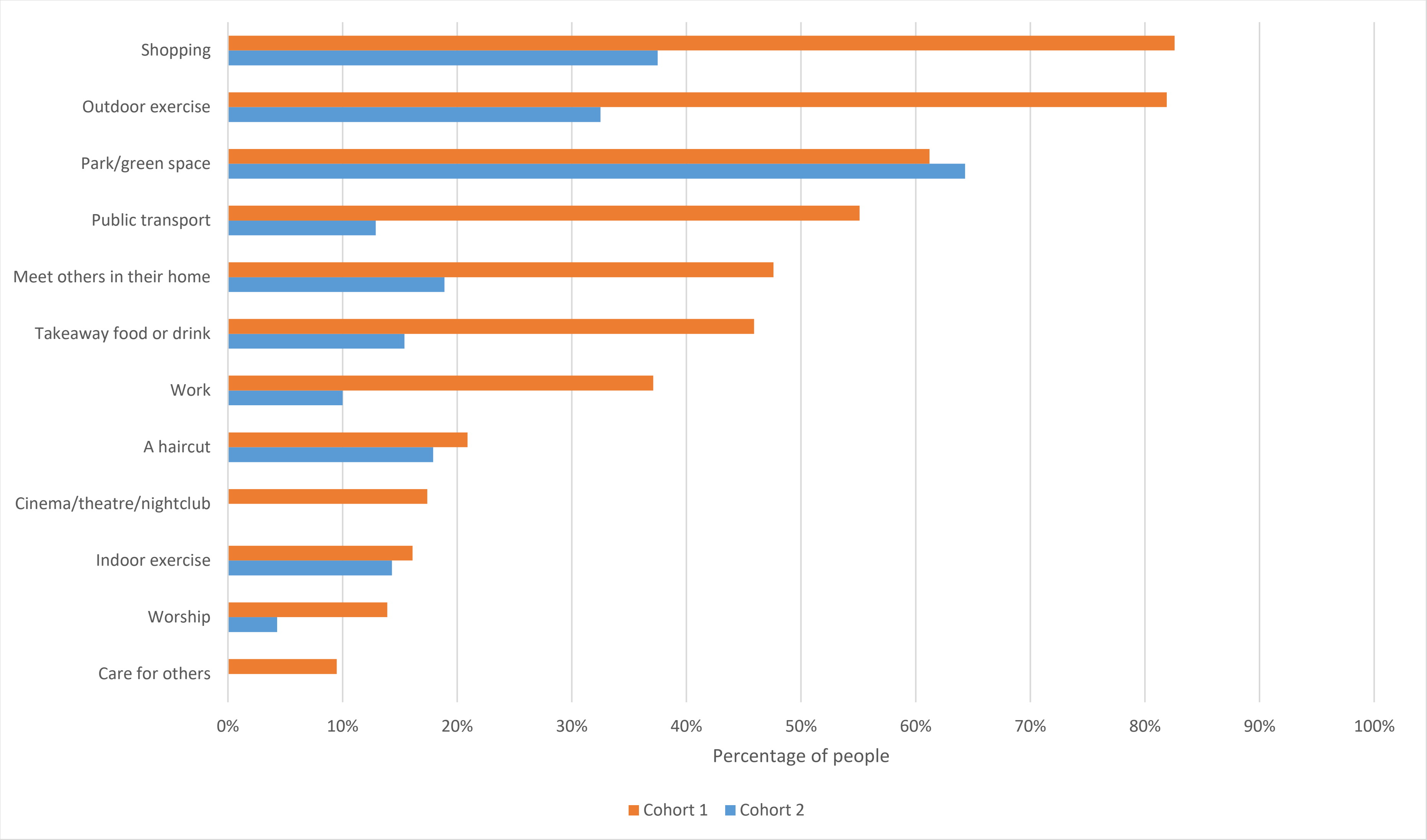

Figure 2.40. Reasons that people with learning disabilities left their house in the last week

For people in Cohort 1, the most frequently reported reasons for people with learning disabilities leaving the house in the last week were to go shopping (83%), for outdoor exercise (82%), and to go to a park or green space (61%). In Cohort 2, the most frequently reported reasons for people with learning disabilities leaving the house were to go to a park or green space (64%), shopping (38%), and for outdoor exercise (33%).

We also asked participants in both cohorts whether they (Cohort 1), or the person they support/care for (Cohort 2) had returned to everywhere they used to go before the COVID-19 pandemic. These data are presented in Figures 2.41 and 2.42 below.

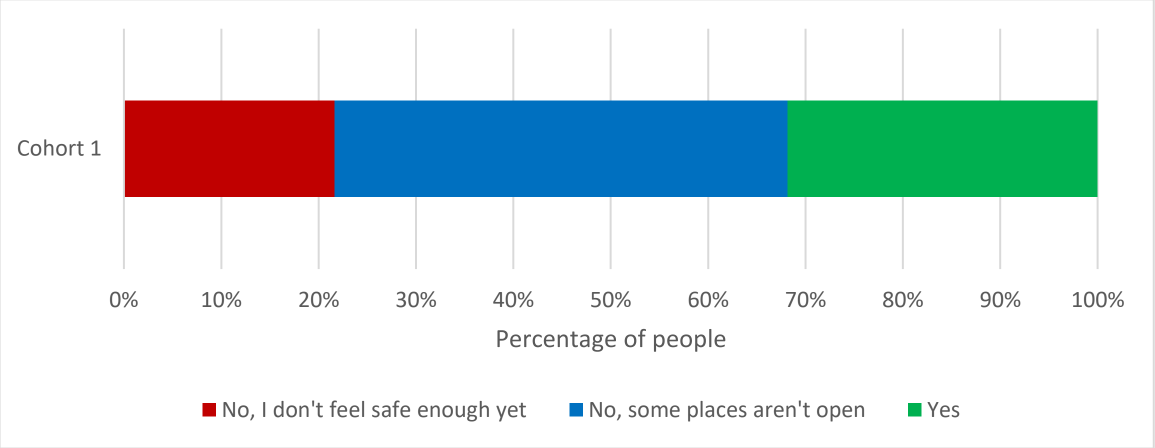

Figure 2.41. Have you been back to everywhere you used to go before the COVID-19 pandemic? (Cohort 1 only)

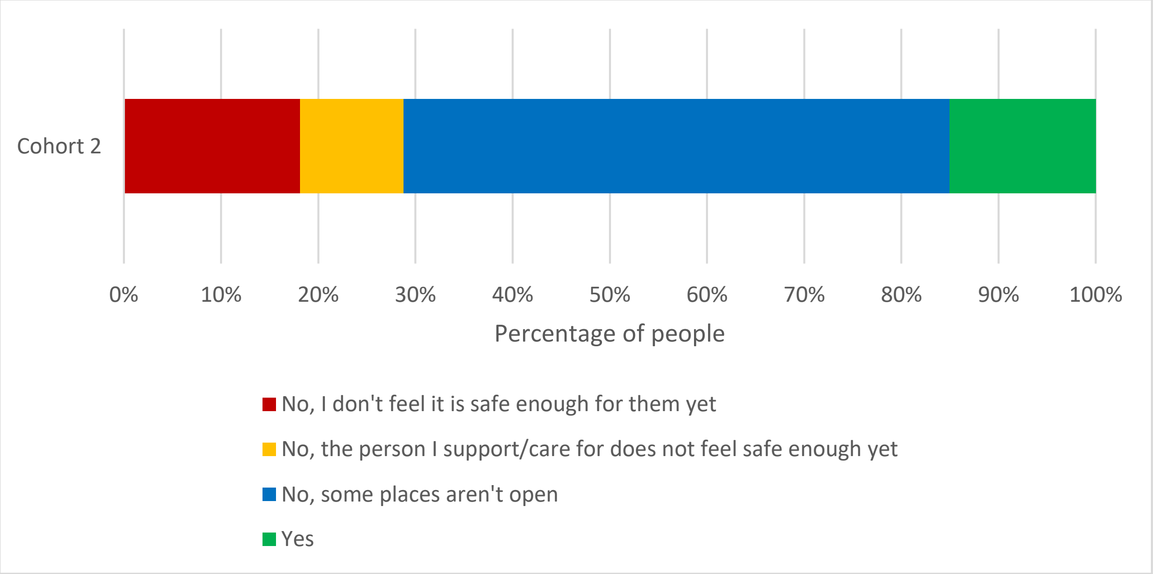

Figure 2.42. Has the person you support/care for returned to everywhere they used to go to before the COVID-19 pandemic? (Cohort 2 only)

In Cohort 1, 35% of people with learning disabilities reported that they had returned to everywhere they used to go before the pandemic, and in Cohort 2 this figure was 16%. We also asked about what would help participants in both cohorts to feel safe enough to return, and these data are displayed in Figure 2.43 below.

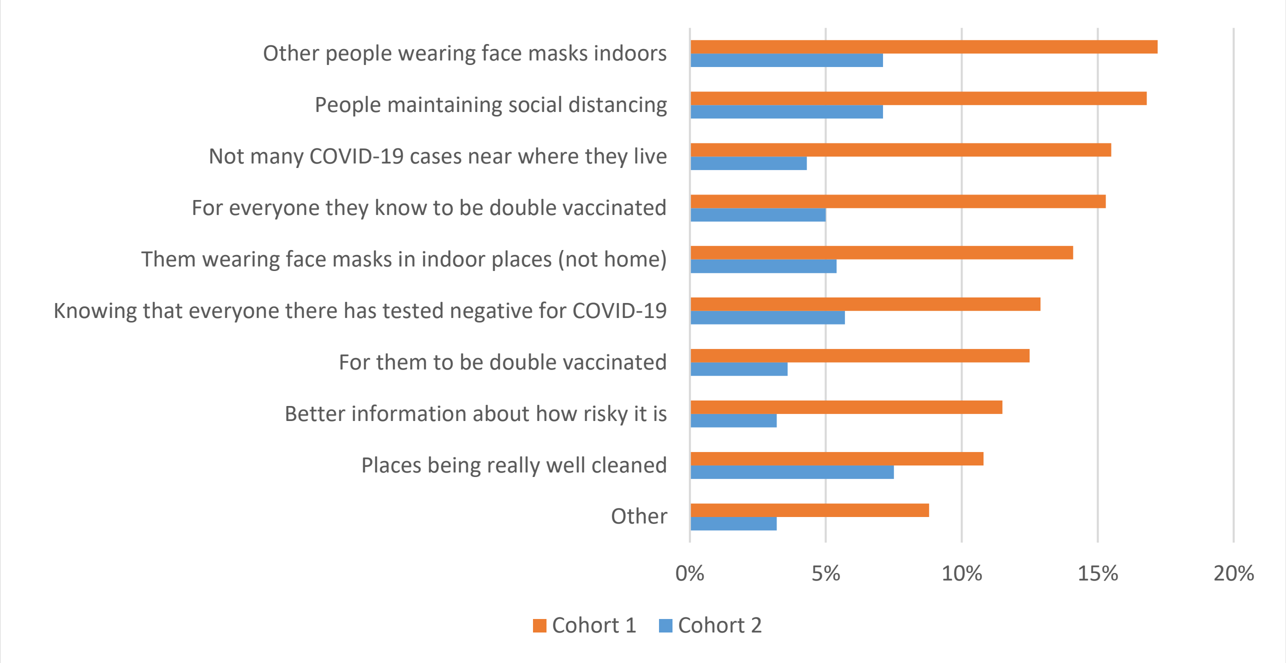

Figure 2.43. What would be needed for people with learning disabilities to feel safe to return to all the places they used to go before the COVID-19 pandemic.

Fewer than 20% of participants in Cohort 1, and fewer than 10% of participants in Cohort 2 reported that any of the actions listed would make it feel safe for people with learning disabilities to return to all the places they used to go before the COVID-19 pandemic. In Cohort 1, the most frequently reported things that would be needed for people with learning disabilities to feel safe enough to return to all the places they used to go would be other people wearing face masks indoors (17%), people maintaining social distance (17%) and not many COVID-19 cases near where they live (16%). In Cohort 2, the most frequently reported things that would be needed for people with learning disabilities to feel safe enough to return to all the places they used to go would be places being really well cleaned (8%), other people wearing face masks indoors (7%) and people maintain social distance (7%).

2.7.4. Local neighbourhoods

We asked participants in both cohorts some questions about their local neighbourhoods, including about how safe they feel going out, and how friendly they are with people who live nearby. These data are presented in Figures 2.44 and 2.45.

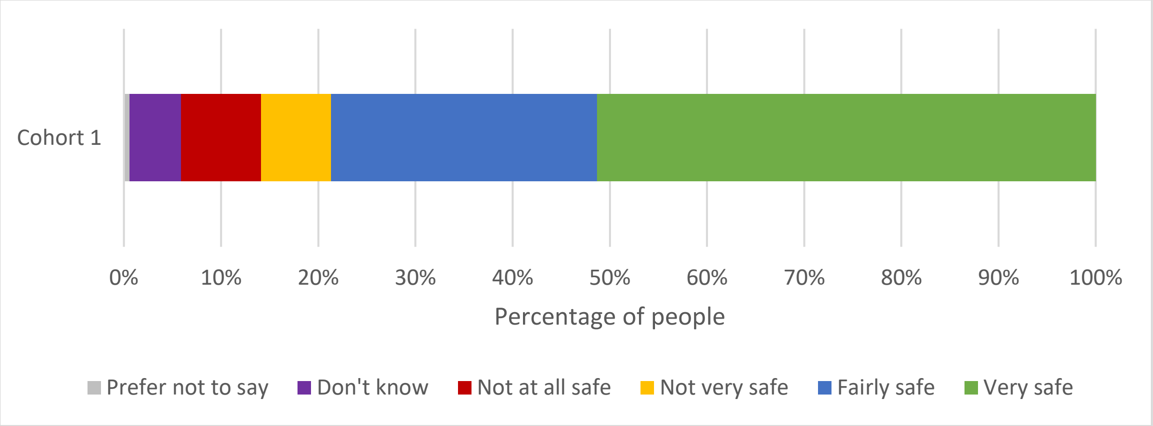

Figure 2.44. Thinking about where you live, how safe would you feel walking on your own during the day in a quiet street close to your home? (Cohort 1 only)

People with learning disabilities in Cohort 1 most frequently reported that they felt very safe when walking alone during the day in a quiet street close to their home (51%).

We asked participants in both cohorts about whether they (Cohort 1), or the person they support/care (Cohort 2) for had become friendly with the people near where they live. These data are presented in Figure 2.45 below.

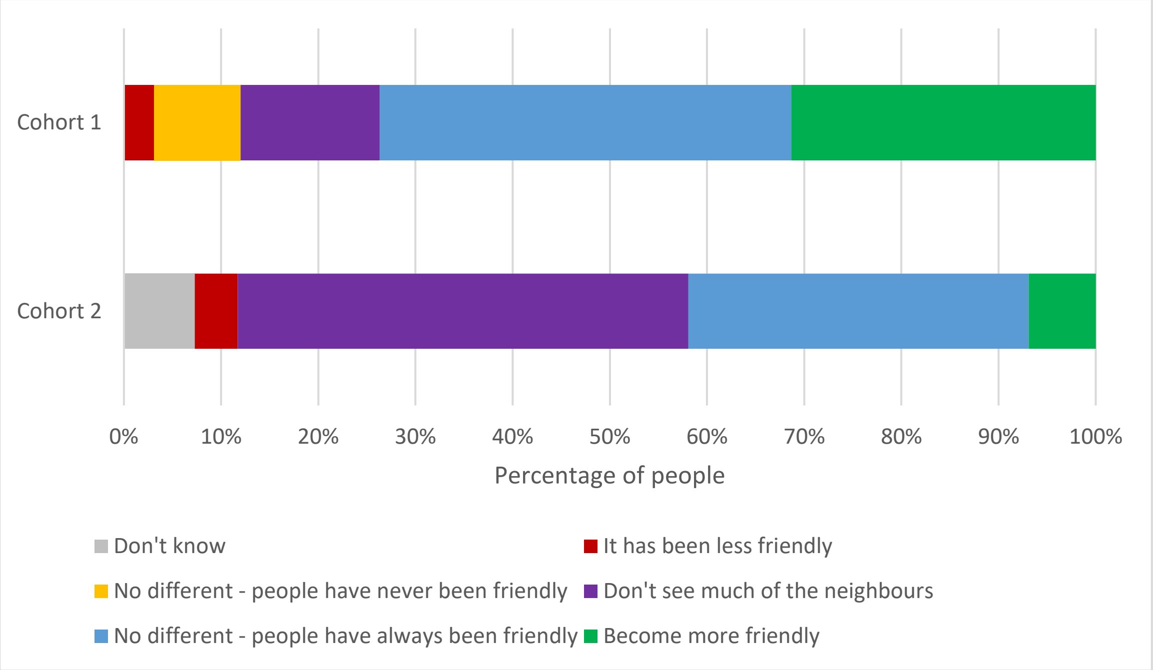

Figure 2.45. How friendly people with learning disabilities were with the people they live near since the start of the COVID-19 pandemic

A large percentage of people with learning disabilities in Cohort 1 reported that people have always been friendly with me near where I live, and that there had been no difference since the start of the COVID-19 pandemic (42%). In Cohort 2, a large percentage family carers and paid support staff of people with learning disabilities reported that the person they support/care for did not see much of the neighbours (46%).

We asked participants in both cohorts if they could tell us anything about the friendliness or unfriendliness of the neighbourhoods. Some of these comments are presented in Box 2.5.

Cohort 1

“Where I live people don't even look at you or say hello....it's everyone for themselves.”

“Since things have calmed down, I have had more interaction with my neighbours than I had before the pandemic.”

“People didn't used to talk to me. Now neighbours speak to me. For example, one neighbour will post letters and get shopping etc. We're quite close friends now and I would do the same for her.”

“People are more worried about keeping their distance and won't talk to you.”

“Many people in my neighbourhood who I have not been able to see and have not seen me we've been quite happy to see each other now because when we see each other before it wasn't so special as what it is now.”

"There's been some conflict and me, mum and my brother have all been involved its affected us all"

"I feel that because I am vulnerable people will take advantage of me".

"Because we all had to go through the same thing. So, we did things to support each other. You have to help people, you just can't help yourself, you have to help others."

Cohort 2

“Most of the neighbours are very friendly towards my son but not the same can be said in the town when he goes to work Here people are not at all friendly especially younger people.”

“Neighbours are looking out for each other.”

“His neighbours have become more available.”

“Involved in street birthday celebration. Decorated houses to help celebrate her birthday and music in the street.”

Box 2.5. Please tell us more about the friendliness of the neighbourhood

In both cohorts, most people expressed that they had become more friendly with their neighbours, with some people identifying that this was because they had been through the same thing, or because they have been able to see each other more. Some people in Cohort 1, however, reported having negative experiences with their neighbours or still maintaining a distance because of worries about COVID-19.

2.7.5. Employment

In Cohort 1, 137 people with learning disabilities (28%) reported that they had a paid job at the moment. In Cohort 2, nine participants (3%) reported that the person they support/care for had a paid job at the moment. Table 2.22 presents these data in more detail.

Table 2.23. Employment of people with learning disabilities

	Cohort 1	Cohort 2
Paid job at the moment		
Yes	28%	3%
Not working, but job being held open	3%	<1%
No	69%	96%
Change of hours		
More hours now	13%	10%
No change	70%	70%
Fewer hours now	17%	20%

Of the people with learning disabilities in Cohort 1 who had a job at the moment (n=137), 70% reported that they had the same hours now than before the pandemic started. This was also the case for 70% of people with learning disabilities in Cohort 2. We also asked people in Cohort 1 about whether they were working at home at the moment, and of the 137 who had a paid job, 37% said that they were currently working at home.

We also asked about volunteer work and Table 2.24 presents data about this.

Table 2.24. Current volunteer work

	Cohort 1	Cohort 2
Volunteer job at the moment		
Yes	34%	9%
Not at the moment, but job is being held open	5%	4%
No	62%	87%

In Cohort 1, 39% of people with learning disabilities had a volunteer job, whether or not they were currently working. In Cohort 2, a smaller percentage (13%) of people with learning disabilities had a volunteer job.

2.7.6. Money

Participants in Cohort 2 were asked about the finances of the person they support/care for. These questions included whether people with learning disabilities had enough money at the moment, 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 2.46-2.48.

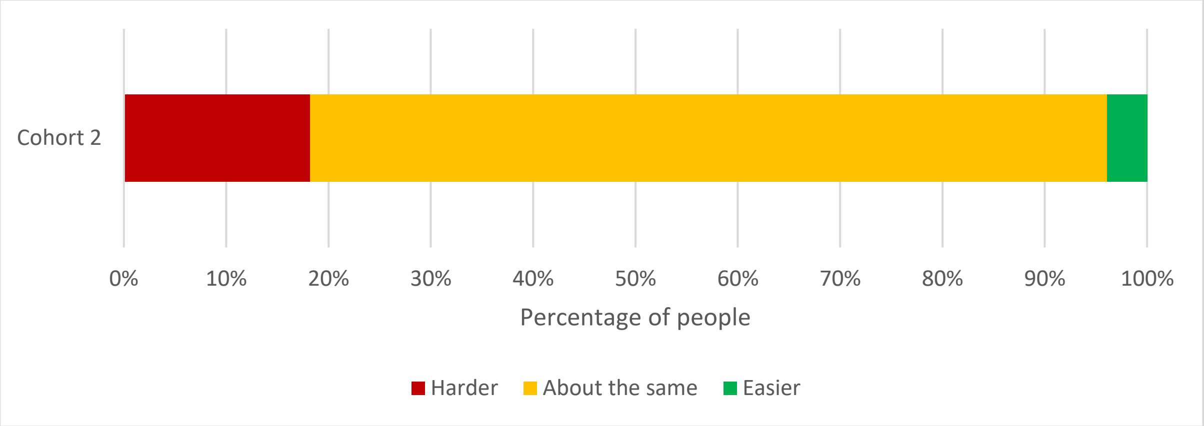

Figure 2.46. Has it been easier or harder for the household bills to be paid where the person you support/care for lives than before the start of the first lockdown in March 2020? (Cohort 2 only)

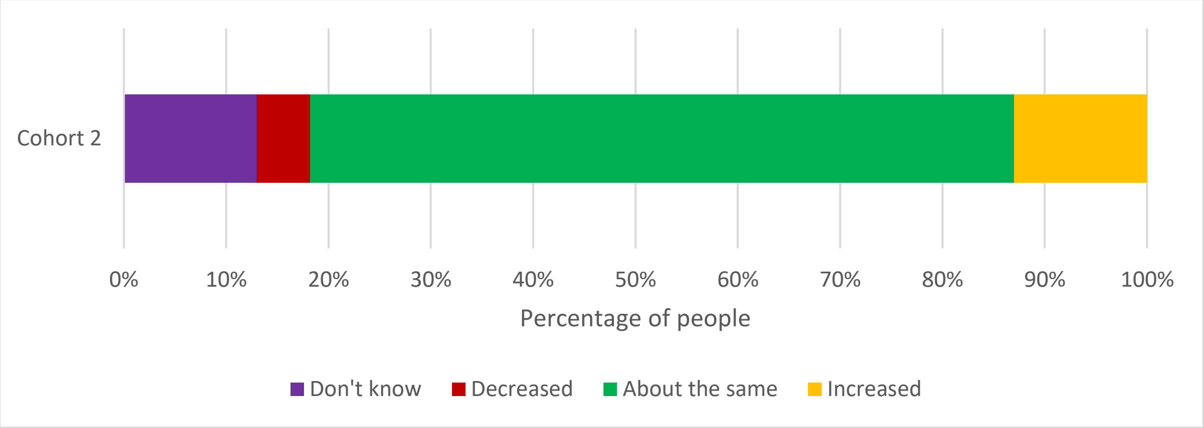

Figure 2.47. Has the amount of benefits the person you support/care for get changed the start of the first lockdown in March 2020? (Cohort 2 only)

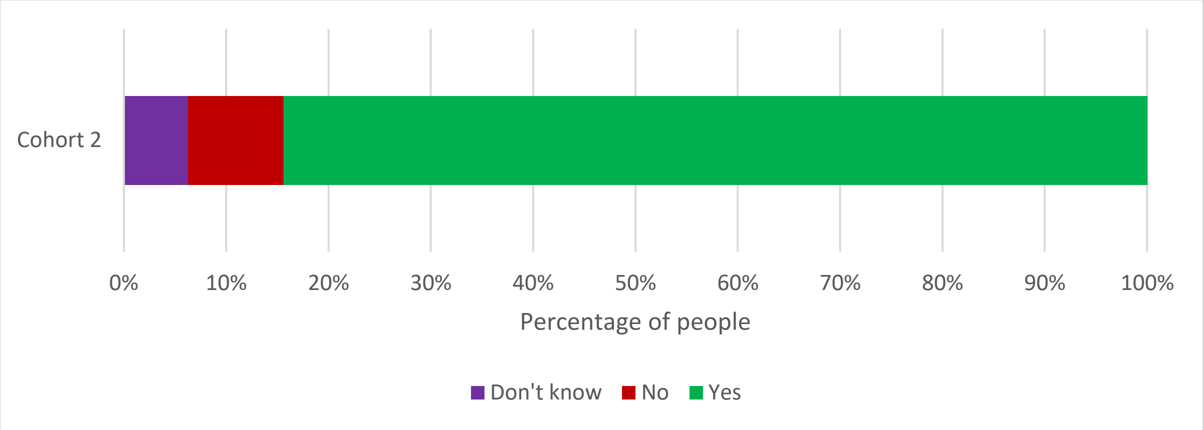

Figure 2.48. Does the person you support/care for have enough money at the moment? (Cohort 2 only)

The majority of family carers and paid support workers (78%) in Cohort 2 reported that there hadn’t been any difference in whether it was easy or hard to pay household bills where the person with learning disabilities lived since the start of the

COVID-19 pandemic. Most people with learning disabilities in Cohort 2 (69%) had not seen any change in the amount of benefits they received since the start of the COVID-19 pandemic. Most people with learning disabilities in Cohort 2 (84%) have enough money at the moment.

2.8. Future considerations

In both cohorts, we asked some open-ended questions about the lives of people with learning disabilities in the near future, including:

- how long it would be until their lives went back to normal,
- what supports would be needed in case of another lockdown,
- what things they were looking forward to doing over the Summer, and
- whether they had a holiday planned.

2.8.1. Life returning to normal

Figures 2.49 and 2.50 display the data about when people with learning disabilities in Cohort 1 and family carers and support workers in Cohort 2 estimate their lives will return to normal.

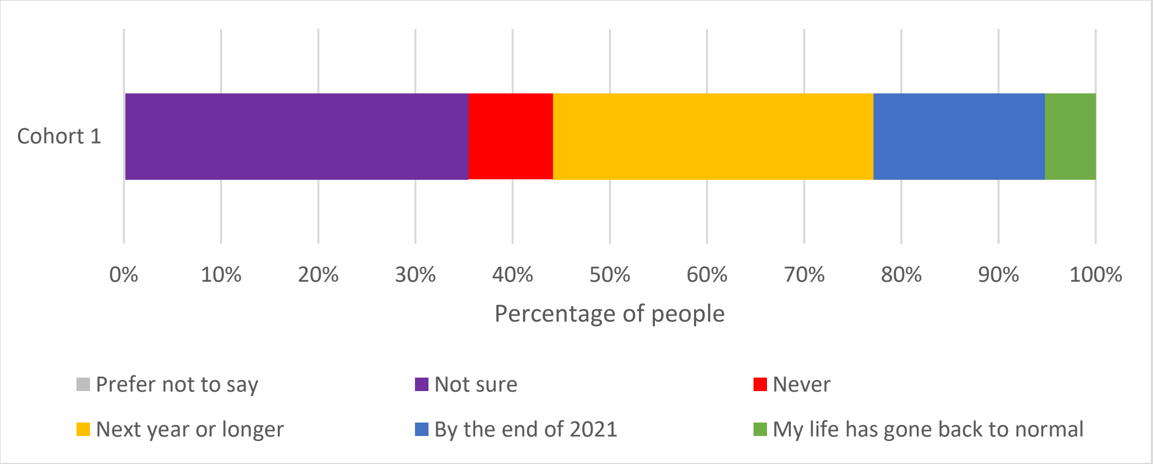

Figure 2.49. How long do you think it will be before your life goes back to how it was before the COVID-19 pandemic? (Cohort 1 only)

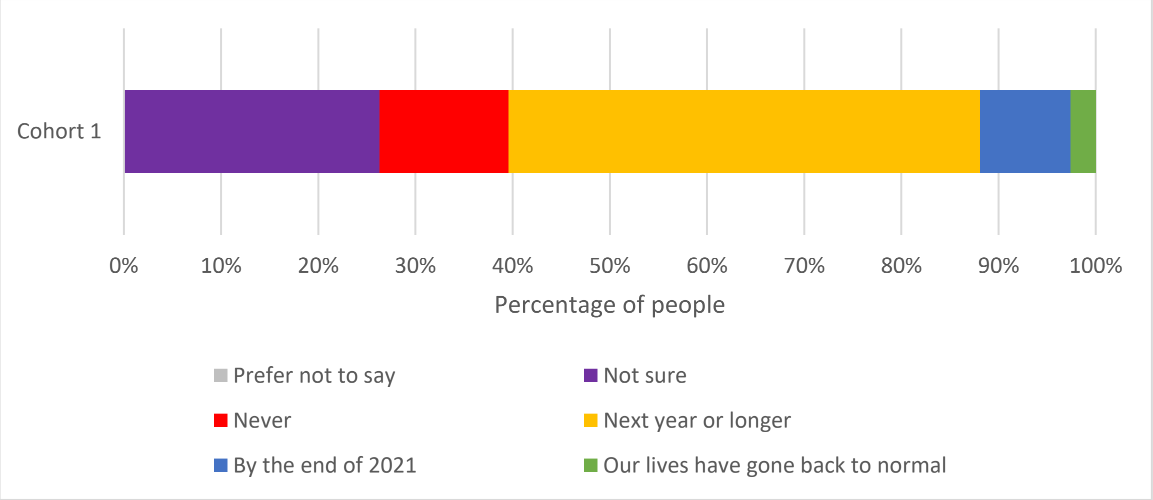

Figure 2.50 How long do you think it will be before your life/the life of the person you support/care for returns to how it was before the COVID-19 pandemic? (Cohort 2 only)

In Cohort 1, the majority of people with learning disabilities reported that they were not sure when their life would return to how it was before the COVID-19 pandemic (35%), or that it would return to pre-pandemic normality by next year or longer (33%). In Cohort 2, almost half of participants (49%) reported that they thought their life/the life of the person they support/care for would return to normal next year or longer.

2.8.2. Future lockdown planning

Participants in both cohorts were asked what support would be needed for them (Cohort 1), or the person they support (Cohort 2), should there be another lockdown. These data are displayed in Figure 2.51.

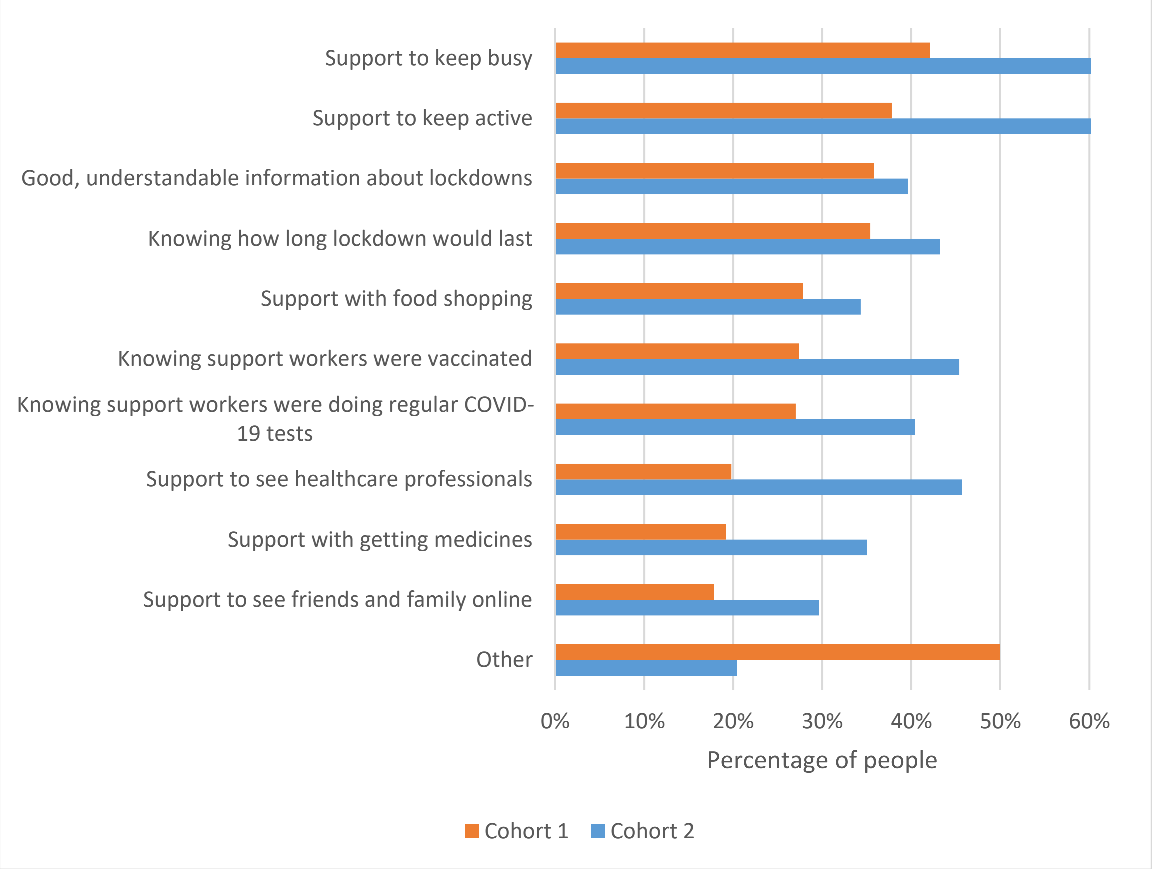

Figure 2.51. Support needed to make a future lockdown easier for people with learning disabilities

In Cohort 1, the most frequently reported things that would be needed to make a future lockdown easier would be support to keep busy (42%), support to keep active (38%) and good, understandable information about lockdowns (36%). In Cohort 2, the most frequently reported things that would be needed to make a future lockdown easier would be support to keep active (71%), support to keep busy (63%) and support to see healthcare professionals (46%). For both cohorts, there was a large number of participants who selected the ‘Other’ option, with responses including that the participant didn’t know, family contact, increased support, and that they did not want another lockdown.

2.8.3. Plans for the Summer and holidays

We asked participants in both cohorts about what they (Cohort 1), or the person they support/care for (Cohort 2), were looking forward to doing during Summer (2021). Some of the responses to this question are presented in Boxes 2.6-2.7 below.

"I want to be able to get out and about more, see more of my friends and spend more time with my family."

'During the lockdown I didn't know what to do with myself. I'm looking forward to swimming and bingo, it won't matter how long it takes for things to happen I know it will. I feel a lot more positive getting out to do more, seeing my family, going to Sainsburys. I'm a lot more confident now and positive keeping busy and occupied and out of trouble."

"Feeling of freedom without having to watch a news report and just go back to watching football and wee things like that."

"To be able to go and see my gran in Germany."

"I am looking forward to everything opening as normal and when there's no masks but please keep the 2-metre distancing in queues."

"Kissing my girlfriend and being close, being back to work and going on transport and to the cinema and things like that'."

"Don't know - just stay in."

"Everything has gone back to normal now so there is nothing I am not doing".

"Go on holiday!"

"I don't even want to hope."

"I don't know because I am still worried about whether I should go outside I would love to go to a restaurant or pub but there is still concerns if I should. I have not left since the first day before the first lockdown."

"I suppose just being normal again and being around the town and having picnics."

"I want a job that pays."

"Getting my hair cut because when the coronavirus happened I could not cut my hair and have a shave and help myself look presentable."

"A bit of travelling and going to see all our family and friends and also weddings that were to happen."

Box 2.6 There are things we haven't been able to do because of coronavirus. What are you looking forward to doing this Summer when we can do more again? (Cohort 1 only)

“A holiday, but guidance and support for people with learning disabilities travelling abroad is abysmal.”

“Being able to have spontaneous visits to places of interest, theatre etc.”

“What is there to look forward to when you live within an institutional, secure-type setting?”

“To go out more and meet friends and also do more activities that he used to do such as bowling and attending larger events such as football games.”

“The person I support with other family members does not do much away from the family home, so Coronavirus has not had a huge impact on what they do.”

“Swimming, I think, when the pool offers more opportunities to book spaces.”

“Seeing friends and family and just being able to laugh and chat with everyone.”

“Nothing they are too scared for own health.”

“Lives in the moment - doesn't look forward!”

“Having a hug and being able to see us with no full PPE on. Being able to play with him and interact. Being able to take him out to open spaces for walks and fresh air.”

Box 2.7. There are things we haven’t been able to do because of coronavirus. What is the person you support/care for looking forward to doing this Summer when we can do more again? (Cohort 2 only)

Most of the things that people with learning disabilities in both cohorts were looking forward to were everyday things like being able to go out again, seeing family, friends, and partners. Some people wanted to go on holiday, and some had already planned them. A small number of people said that they weren’t looking forward to doing anything because they were still worried about COVID-19. Other participants, in Cohort 2 specifically, reported that the person they support did not, or could not, do many things before COVID-19 and so this question was not relevant for them.

We also asked participants in both cohorts about planned holidays, and these data are presented in Figure 2.52.

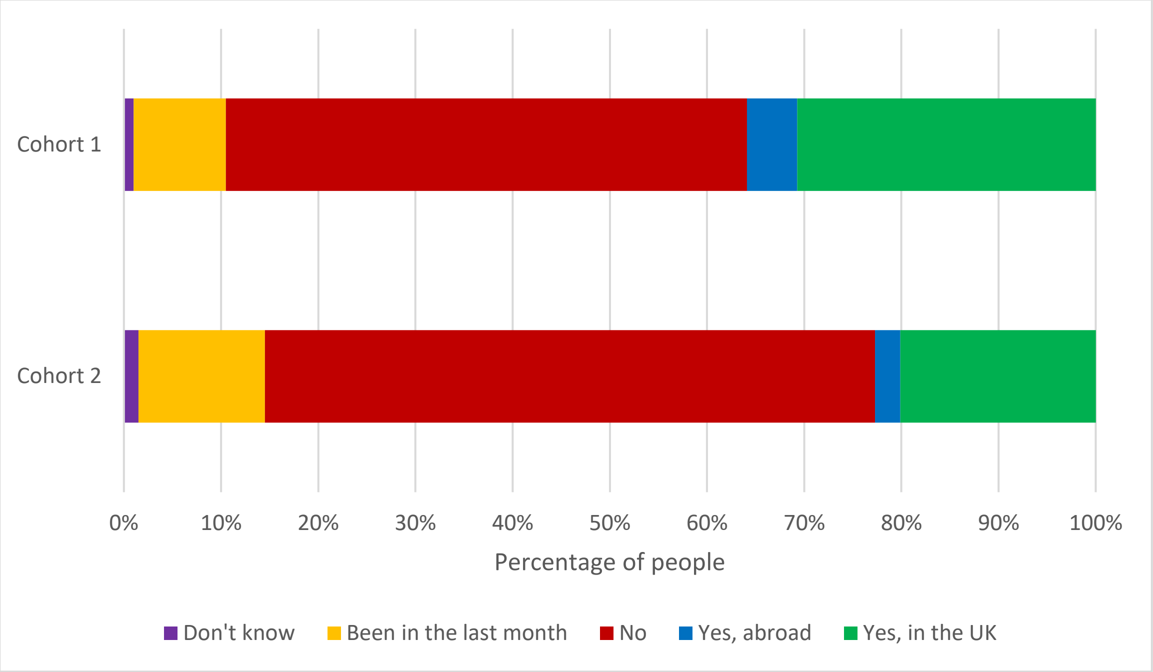

Figure 2.52. Planned holidays for people with learning disabilities

In Cohort 1, 36% of people with learning disabilities had a holiday planned, either in the UK or abroad. In Cohort 2, this figure was 23%.

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 in the last four weeks. These data are presented in Figure 3.1.

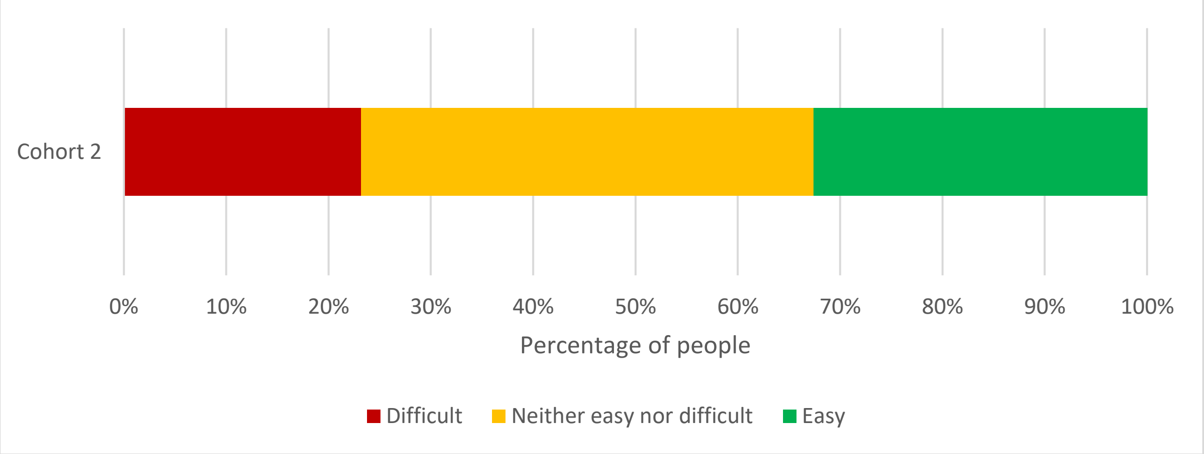

Figure 3.1. In the last four weeks, how easy has it been for you to find accurate information about how COVID-19 affects you as a family carer or paid support worker? (Cohort 2 only)

From this figure, we can see that 23% of people in Cohort 2 found it difficult to find accurate information about COVID-19.

As the rules changed during the interview/survey period, we asked participants about how they found out about changes to COVID-19 rules. 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.

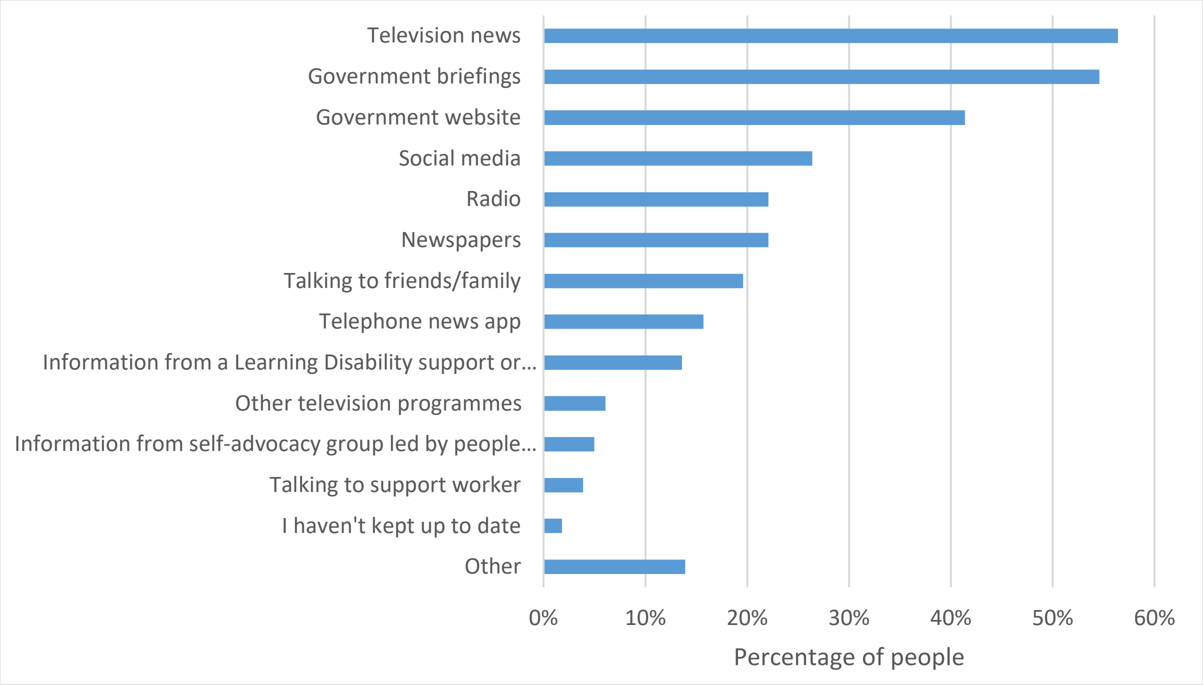

Figure 3.2. How do you find out about changes to COVID-19 rules/information? (Select all that apply) (Cohort 2 only)

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 news was the most popular means of finding out about changes to COVID-19 rules and information (69% in Cohort 1, 56% in Cohort 2), but family carers/paid support staff in Cohort 2 were more likely to watch government briefings (55%), use government websites (41%) and radio (22%) compared to people with learning disabilities in Cohort 1 (31%, 11% and 11% respectively).

We also asked participants in Cohort 2 about whether they thought there should be any restrictions (like wearing face masks or social distancing) right now on what people can do because of COVID-19. These data are displayed in Figure 3.3 below.

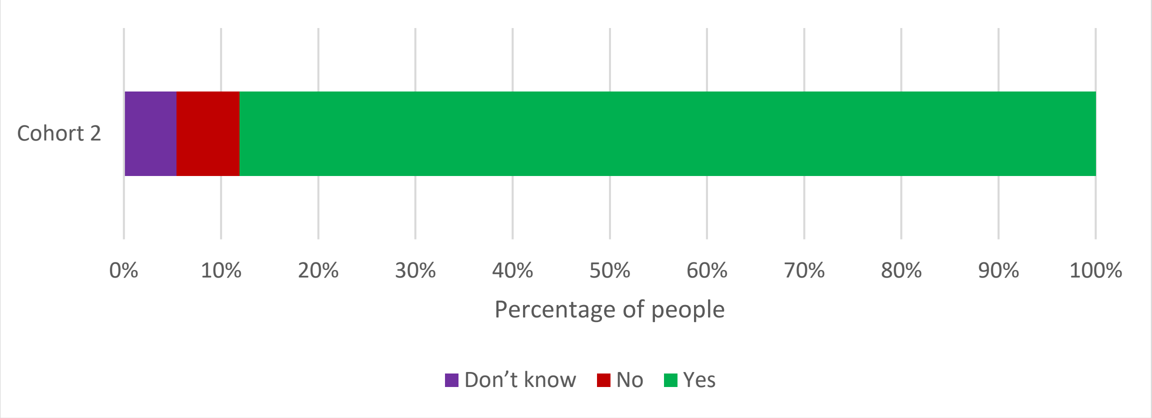

Figure 3.3. Do you think there should be any restrictions, like wearing face masks or social distancing, right now on what people can do because of COVID-19?

In Cohort 2, the most frequently reported answer was that there should be COVID-19-related restrictions right now (88%).

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, which we will report on separately to explore changes over time.

We asked family carers and paid support staff about their general health, feelings of happiness and anxiety. These are displayed in Table 3.1 below.

Table 3.1. The current health status of family carers and paid support staff of people with learning disabilities

		Cohort 2
Health today		
	Excellent	4%
	Very good	19%
	Good	43%
	Fair	26%
	Poor	8%
Overall, how happy did you feel yesterday, on a scale of 0 to 10 where 0 is "not at all happy" and 10 is "completely happy" (mean [SD])		6.17 [2.06]
Overall, how anxious did you feel yesterday, on a scale of 0 to 10 where 0 is "not at all anxious" and 10 is "completely anxious" (mean [SD])		4.95 [2.56]

When asked about their general health today, family carers and paid support staff of people with learning disabilities in Cohort 2 most commonly rated their health as good (43%). The average score for how happy family carers and paid support staff felt yesterday was 6.17, indicating that they were quite happy. The average score for how anxious family carers and paid support staff felt yesterday was 4.95, indicating that they were moderately anxious.

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 3.4 below.

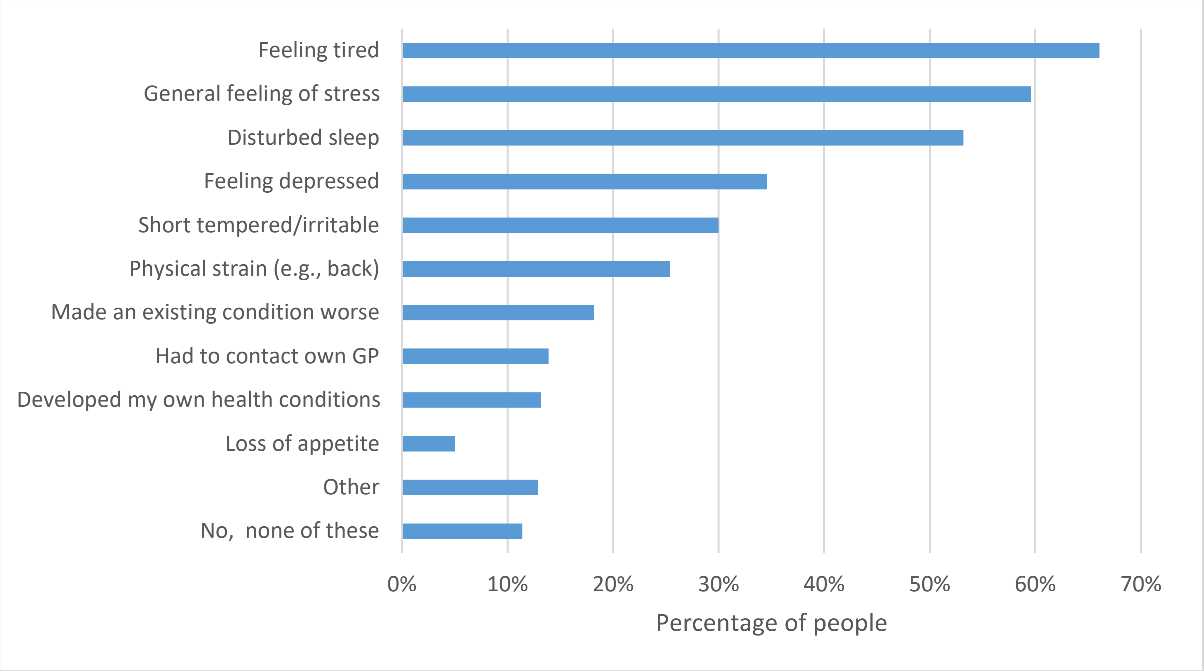

Figure 3.4. In the last four weeks, has your health been affected by your caring role in any of these ways? (Select all that apply)

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 feeling tired (66%), a general feeling of stress (60%), or disturbed sleep (53%). Thirty-nine (14%) carers reported having to contact their own GP in the last 4 weeks regarding their health.

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 the label "Profound and Multiple Learning Disabilities (PMLD)" applies[12] from the Cohort 2 surveys.

4.1. Descriptive data about people with PMLD

In Cohort 2, at Wave 3 (n=118) 44% of participants were supporting/caring for people with PMLD. Because we did not ask this question at Wave 3, data regarding whether the person had PMLD were used from Wave 1 and Wave 2.

Demographic data (e.g., age, gender, ethnicity) were not asked of participants in Wave 3, and required data linkage from the Wave 1 and Wave 2 databases. The priority for this report was to share a comprehensive set of findings from the Wave 3 survey as quickly as possible after data collection finished, so the data linkage was not completed for the purposes of this report. These data are available for people with PMLD at Wave 1, in Chapter 4 of the Wave 1 Full Report[13]. Based on our participant retention rates from Wave 1 (Cohort 2: 74%), we anticipate that the demographic data at Wave 3 will be broadly similar. Future published work that draws on the Wave 3 data will present results following data linkage.

Detail about who people with and without PMLD live with is presented in Table 4.1.

Table 4.1. Who people with PMLD live with

	People with PMLD	**People without PMLD**
Live with family with no support from staff	31%	42%
Live with other people in supported living accommodation	11%	14%
Live with other people in residential care	13%	7%
Live in a secure placement	1%	2%
Live in a different type of home (e.g., residential college)	7%	7%
Live with family with support staff coming into their home	29%	16%
Live alone with support staff coming into their home (supported accommodation)	8%	10%
Live alone with no support from staff	0%	0%
Live in a Shared Lives arrangement	2%	1%

The majority of people with PMLD in Cohort 2 lived with family; either with support from staff coming into the family home (29%) or without support from staff coming into the family home (31%). The majority of people without PMLD in Cohort 2 also lived with family, with more people getting no support from staff coming into the family home (42%) than getting this type of support (16%). Substantial numbers of people with and without PMLD lived alone or with others in some form of supported

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[12] 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

[13] https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability/results/wave1results/fullreport/coronavirus_and_people_with_learning_disabilities_study_wave_1_full_report_v1.0_final.pdf

accommodation/supported living (19% and 24% respectively), with fewer people living in residential care (13% and 7% respectively).

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:

- COVID-19-related restrictions,
- tests for COVID-19,
- whether they had had COVID-19,
- whether they had been hospitalised because of COVID-19 symptoms,
- whether they were 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, and
- about COVID-19 vaccinations.

4.2.1. COVID-19 restrictions

We asked participants Cohort 2 about whether they thought there should be any restrictions (like wearing face masks or social distancing) right now on what people can do because of COVID-19. These data are displayed in Figure 4.1 below.

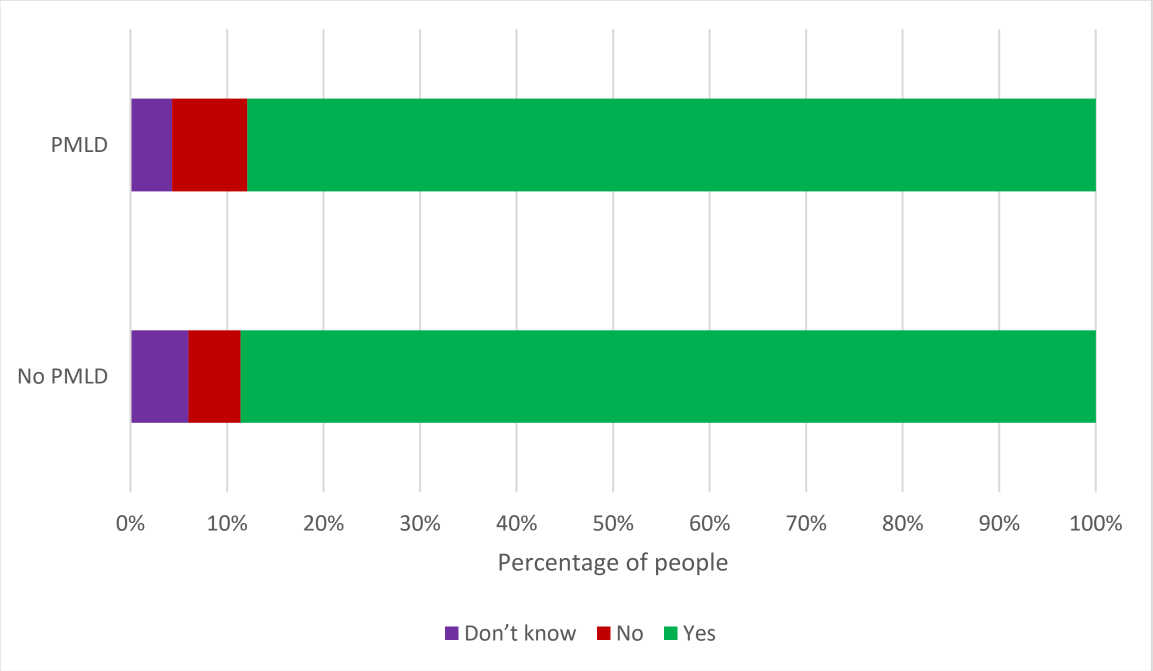

Figure 4.1. Do you think there should be any restrictions, like wearing face masks or social distancing, right now on what people can do because of COVID-19?

The vast majority of family carers/paid support staff of people with PMLD (88%) and people without PMLD (89%) said that there should be COVID-19-related restrictions right now.

When asked about what restrictions they thought that there should be, family carers/ paid support staff of people with and without PMLD most commonly mentioned wearing masks (particularly indoors and on public transport), hand washing/sanitising, and social distancing (including restricting numbers of people on public transport and indoor spaces).

4.2.2. Testing for COVID-19 and having COVID-19

We asked participants in Cohort 2 whether people with and without PMLD had been tested for COVID-19 in the last four weeks. 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. The number of people in both groups who had had a COVID-19 test are displayed in Table 4.2.

Table 4.2. Testing for COVID-19 in the last four weeks

	People with PMLD	**People without PMLD**
Yes – a Lateral Flow Test at home	25%	28%
Yes – a PCR test at home	9%	3%
Yes – a test at home, but unsure of what type	3%	1%
Yes – at a testing centre	2%	4%
No	58%	60%
Don't know	4%	3%

Overall, 38% of people with PMLD and 36% of people without PMLD in Cohort 2 were reported to have had a COVID-19 test. Where tests had been done at home, we asked about the frequency of these tests. These data are displayed in Figure 4.2 below.

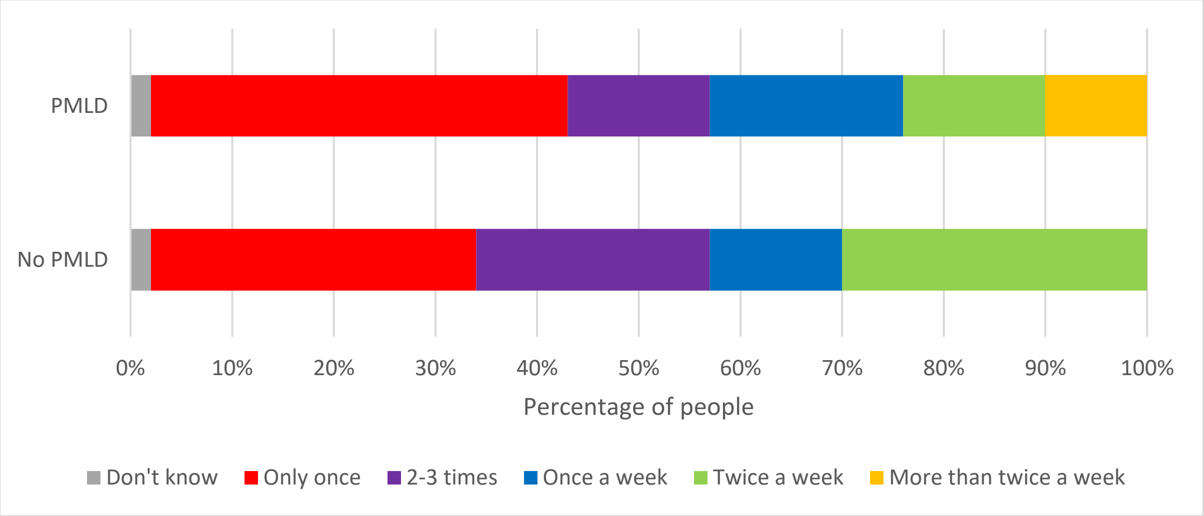

Figure 4.2. In the last four weeks, how many times have they had a test at home?

Of those who had had at least one test, people with and without PMLD most commonly had had tests only once in the last four weeks (41% and 32% respectively), with a substantial proportion of people with and without PMLD having a test at least twice a week (24% and 30% respectively). We also asked about how the tests were done, and for those who had had a test these data are displayed in Table 4.3 below.

Table 4.3. How was the test done? (Select all that apply)

	People with PMLD	People without PMLD
Taught themselves how to do it	2%	7%
Someone showed them how to do it	2%	11%
A family member did it for them	41%	44%
A support worker/paid carer did it for them	41%	28%

For people with and without PMLD, tests were most commonly done by a family member (41% and 44% respectively) or a support worker (41% and 28% respectively) did the test for them.

Reasons for people with and without PMLD having a COVID-19 test are included in Figures 4.3 and 4.4 below.

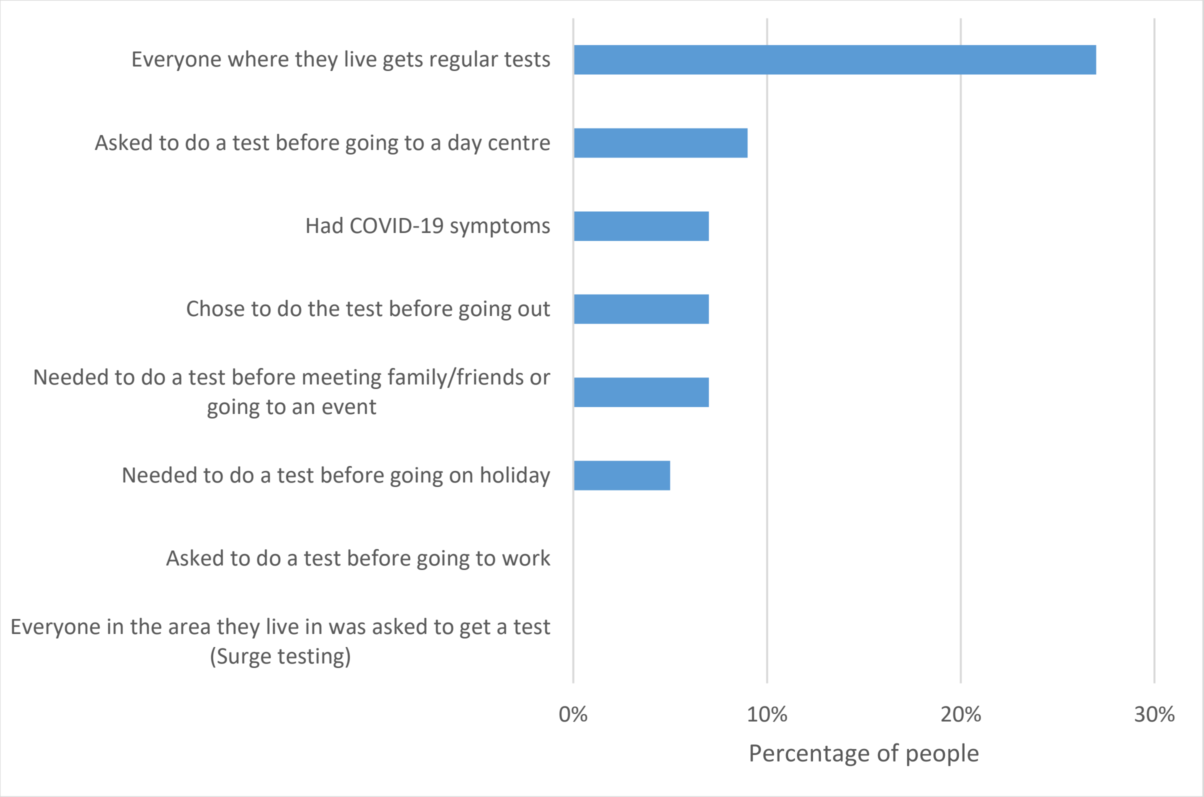

Figure 4.3. Reasons for doing COVID-19 tests (People with PMLD only)

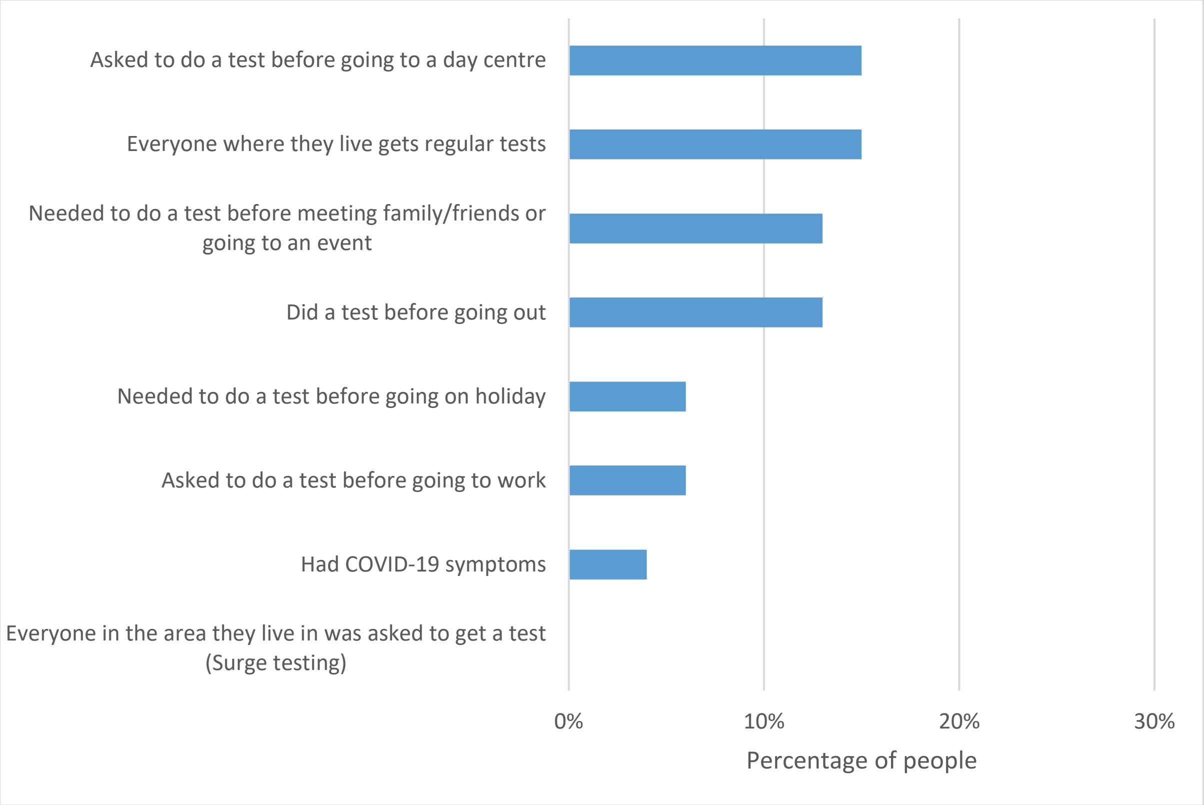

Figure 4.4. Reasons for doing COVID-19 tests (People without PMLD only)

The most frequently reported reasons for doing a COVID-19 test for people with PMLD were everyone where they live getting regular tests (27%) and being asked to do a test before going to a day centre (9%). For people without PMLD, the most frequently reported reasons for doing a COVID-19 test were everyone where they live getting regular tests (15%) and being asked to do a test before going to a day centre (15%).

We also asked family carers and paid support staff in both groups about whether the person they support/care for had had COVID-19. We were interested in cases that had been confirmed by a doctor or a test, as well as cases where it is thought the person had COVID-19 but this was not confirmed by a doctor or test. The data for these questions are reported in Figure 4.5, and are separated into the two groups in Cohort 2 (people with PMLD and people without PMLD).

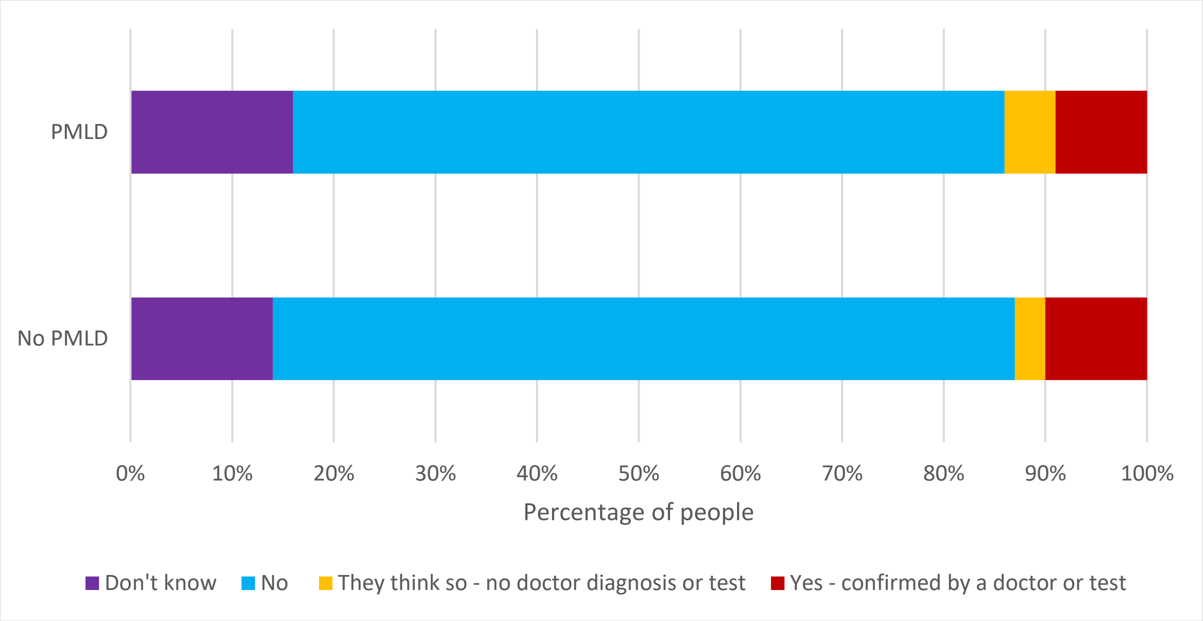

Figure 4.5. Do you think the person you support/care for ever had COVID-19?

By the time of Wave 3, 14% of family carers and paid support staff of people with PMLD thought that the person they cared for had had COVID-19; the proportion was the same reported by 14% of family carers and paid support staff of people without PMLD.

For the people with PMLD, of the 16 people who had a confirmed or suspected case of COVID-19, 5 people (31%) were hospitalised because of their COVID-19 symptoms, compared to 4 (20%) of the 20 people without PMLD.

4.2.3. Shielding and self-isolating

We asked family carers/paid support staff who supported/cared for people with and without PMLD about shielding, asking whether they were shielding at the time of the survey being completed. These data are displayed in Table 4.4.

Table 4.4. Current shielding

	People with PMLD	People without PMLD
Yes – told by a doctor or letter to shield	17%	11%
Yes – self-imposed “shielding”	5%	7%
No	78%	81%
Don’t know	0%	2%

In Cohort 2, 22% of people with PMLD and 17% 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 4.6.

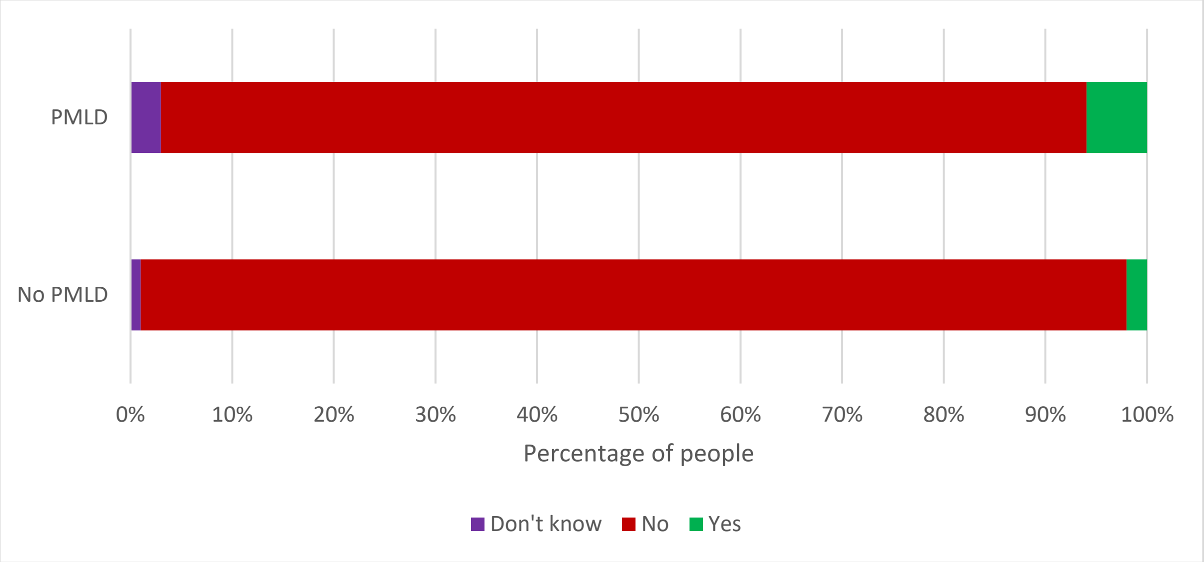

Figure 4.6. Person with learning disabilities self-isolated because of COVID-19 symptoms or close contact with someone who had COVID-19 symptoms

The vast majority of people with learning disabilities in both groups (92% of people with PMLD and 97% of people without PMLD) had not self-isolated.

4.2.4. 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. 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
Yes	54%	41%
No	44%	57%
Don't know	2%	2%

Family carers/paid support staff of people with PMLD were more frequently reported to wear PPE (e.g., masks, gloves, aprons) than for people without PMLD (54% versus 41%).

We also asked whether people with learning disabilities were wearing face masks/coverings when they were going out in the last week. These data are presented in Table 4.6.

Table 4.6. Use of face masks/coverings by people with learning disabilities in the last week

	People with PMLD	**People without PMLD**
Yes – worn a face mask/covering all the time when they were out	12%	32%
Yes – worn a face mask/covering when they were inside (e.g., a shop, a bus or a restaurant)	22%	41%
No – not worn a face mask/covering when they were out	9%	7%
No – not worn a face mask/covering because they can't wear them (e.g., intolerance)	47%	12%
No – not worn face mark/covering because they have not been close to other people while out	3%	5%
Not been out in last week	7%	2%

Fewer people with PMLD (34%) had been wearing face masks/coverings than people without PMLD (73%).

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 3 was about COVID-19 vaccinations. We asked participants about whether the person with learning disabilities had received a COVID-19 vaccination. These data are displayed for people with and without PMLD in Cohort 2, in Figure 4.7.

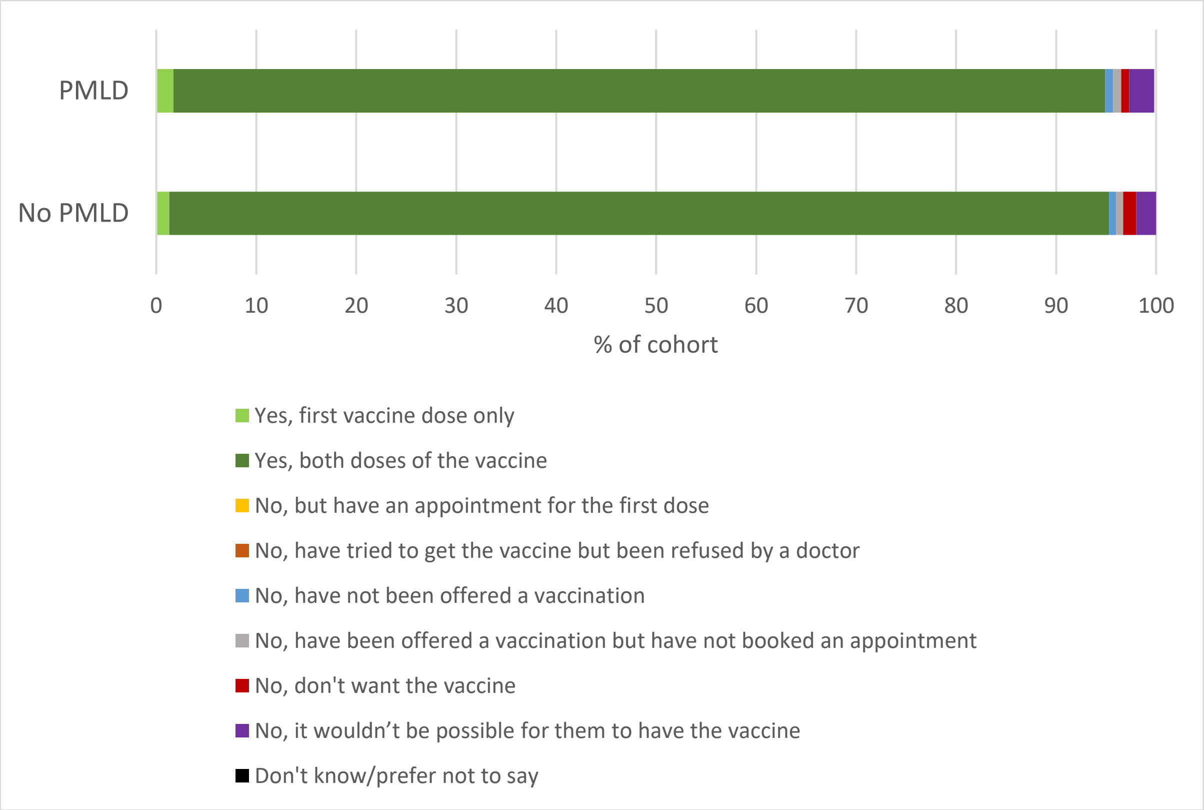

Figure 4.7. COVID-19 vaccination receipt in people with learning disabilities and reasons for non-receipt

The vast majority of participants in both groups (95% of people with and without PMLD) reported that the person they supported/cared for, had received at least one dose of the COVID-19 vaccine. In both groups, at least 93% of people with PMLD and 94% of people without PMLD had received both doses of the COVID-19 vaccination.

When asked about whether the person they support/care for would take a booster COVID-19 vaccination in Autumn/Winter 2021, if this were needed, the vast majority of participants in both groups (93% of people with PMLD; 86% of people without PMLD) indicated that the person they supported/cared for would be willing to have this.

We asked participants in both groups about whether they thought that all paid staff supporting people should have a COVID-19 vaccination. These data are displayed in Figure 4.8.

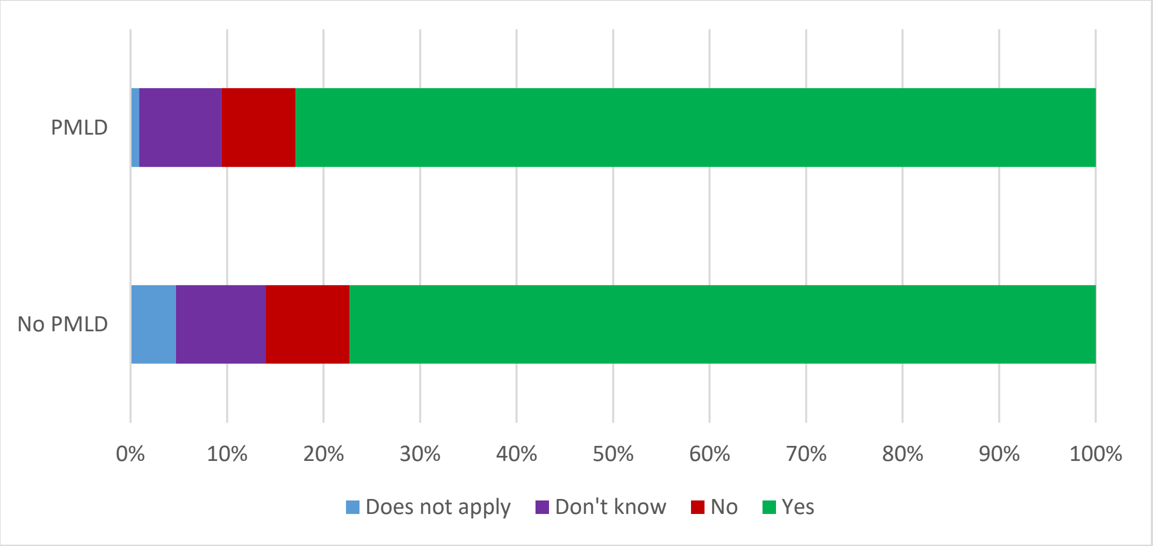

Figure 4.8. Do you think that all the support staff and PAs who support the person you support/care for should HAVE to have the COVID-19 vaccination?

A substantial majority of family carers and paid support staff of people with and without PMLD (83% and 77% respectively) reported that they thought that paid support staff and PAs should have to have the COVID-19 vaccination.

4.3. Physical health and access to health services

In this sub-section, we report the findings from the Cohort 2 survey about the physical health of people with learning disabilities and their access to health services during the COVID-19 pandemic, broken down 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,
- contact with healthcare professionals,
- what has happened to planned medical tests, appointments and operations, and
- what is happening with annual health checks.

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 (45%). Family carers/paid support staff of people without PMLD reported the health of the person they support/care for as good (49%). We also asked about new and worsening health conditions in the last four weeks. All data for these questions are displayed in Table 4.7.

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

	People with PMLD	People without PMLD
Health today		
Good	45%	49%
OK	37%	34%
Not very good	17%	
Not good		15%
Don’t know	1%	1%
New or worsening health conditions in the last four weeks (excluding COVID-19)		
Yes	30%	26%
No	66%	74%
Don’t know	4%	0%

Of the 30% of people with PMLD who had a new or worsening health condition in the last four weeks (excluding COVID-19), 86% reported that they had tried to get advice from a doctor, nurse, or pharmacist. For people without PMLD, of the 26% of people with who had a new or worsening health condition in the last four weeks (excluding COVID-19), 84% were reported to have sought advice from a doctor, nurse, or pharmacist.

Participants in Cohort 2 were asked about whether the person they support had been admitted to hospital for a reason unrelated to COVID-19 in the last four weeks; these data are reported in Table 4.8.

Table 4.8. In the last four weeks, has the person you support/care for had a hospital admission for a reason not related to COVID-19?

	People with PMLD	People without PMLD
Yes	9%	3%
No	91%	97%
Don’t know	0%	1%

Of the 10 people with PMLD (9% of all people with PMLD) who had been admitted to hospital for a reason unrelated to COVID-19 in the last four weeks, all of them were allowed to have a carer stay with them during their admission. For the 4 people without PMLD (3% of all people without PMLD), 3 people 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 in the last four weeks, and these data are presented in Figure 4.9.

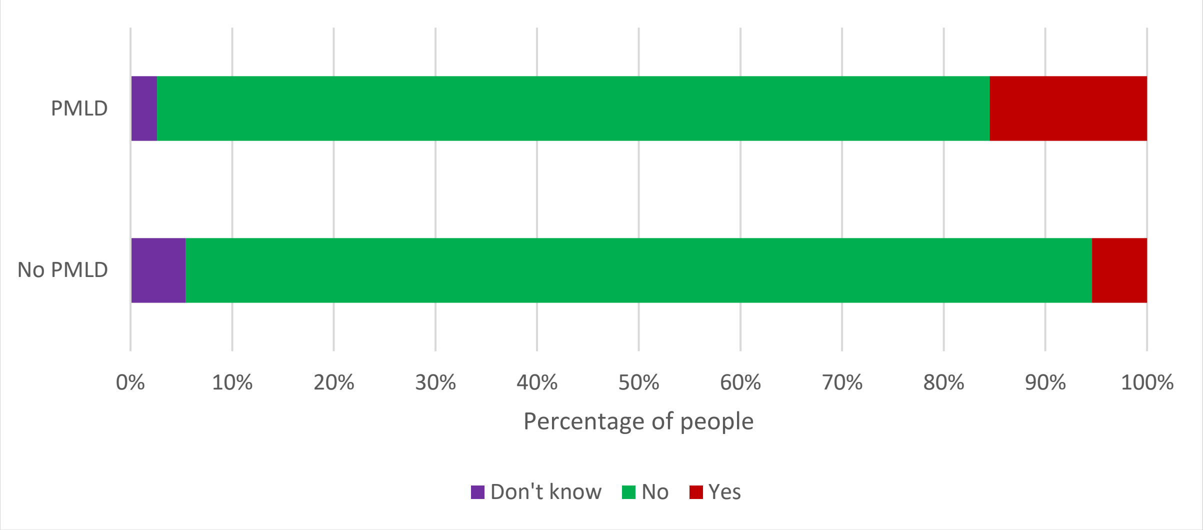

Figure 4.9. In the last four weeks, have there been difficulties getting and keeping essential equipment and resources for the person you support/care for?

In the four weeks before completing the survey, 16% of family carers and paid support staff of people with PMLD had had difficulties in getting and keeping essential equipment for the person they care for. For people without PMLD, this was 5%.

4.3.2. Contact with healthcare professionals

The following figures (Figures 4.10-4.13) present data about whether people with and without PMLD had had contact with healthcare professionals in the four weeks before the survey.

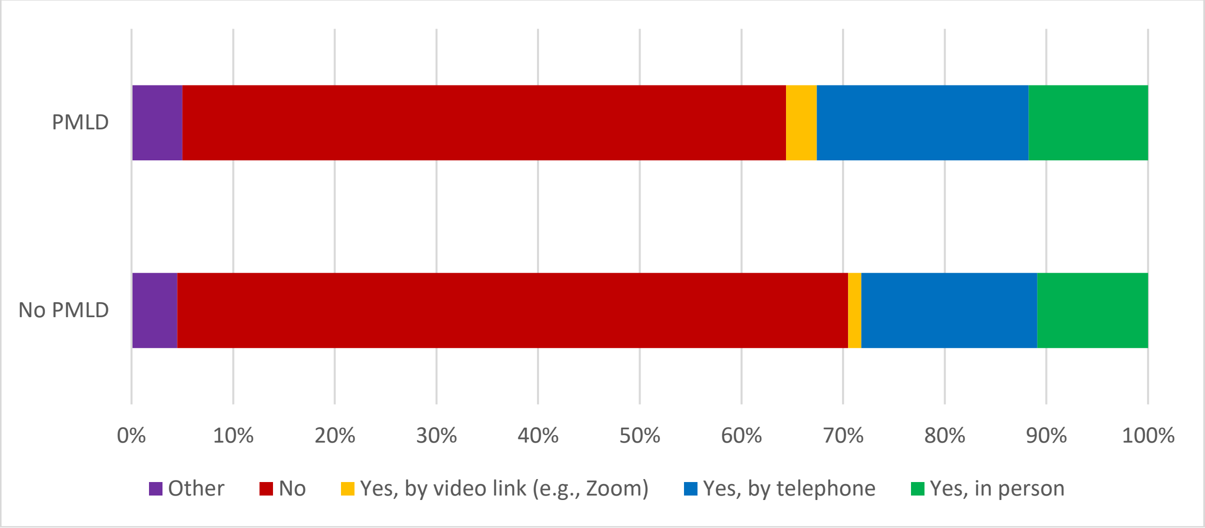

Figure 4.10. In the last four weeks has the person you support/care for been in contact with a GP? (percentage of all Cohort 2 participants with and without PMLD)

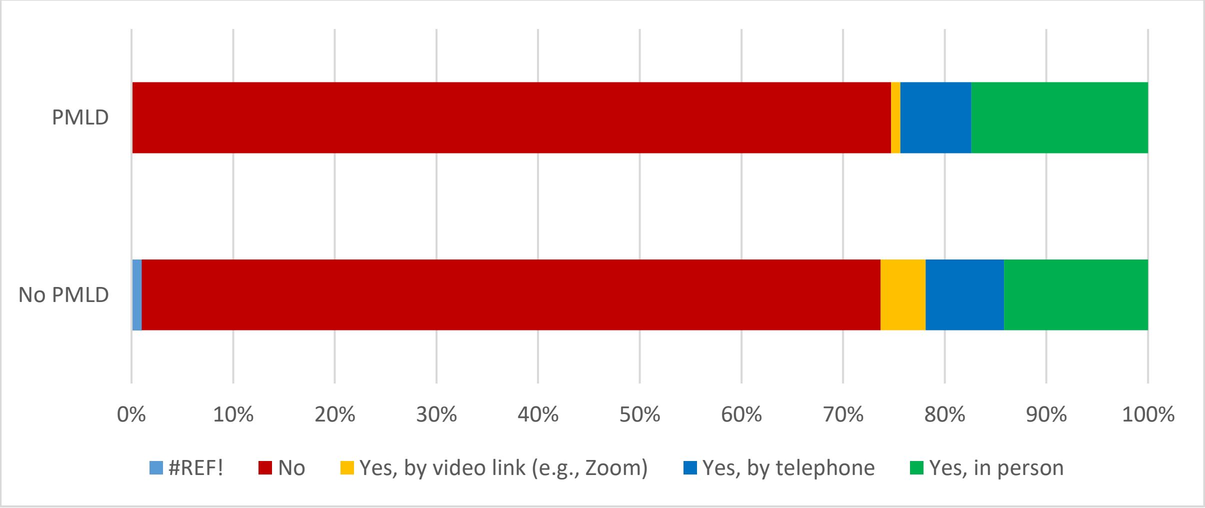

Figure 4.11. In the last four weeks has the person you support/care for been in contact with a community nurse? (percentage of all Cohort 2 participants with and without PMLD)

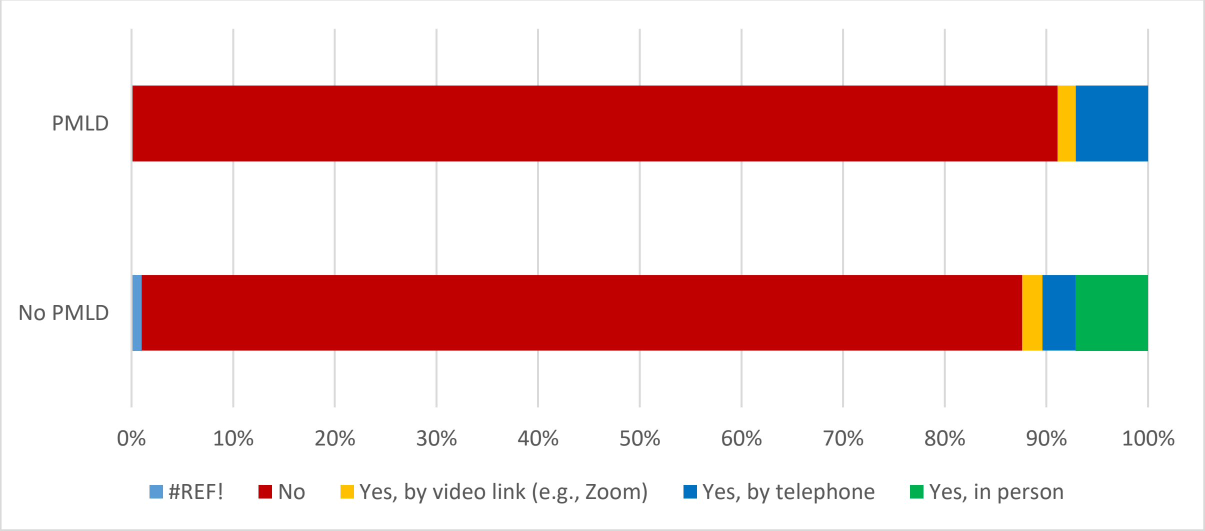

Figure 4.12. In the last four weeks has the person you support/care for been in contact with a Psychiatrist, Clinical Psychologist or Counsellor? (percentage of all Cohort 2 participants with and without PMLD)

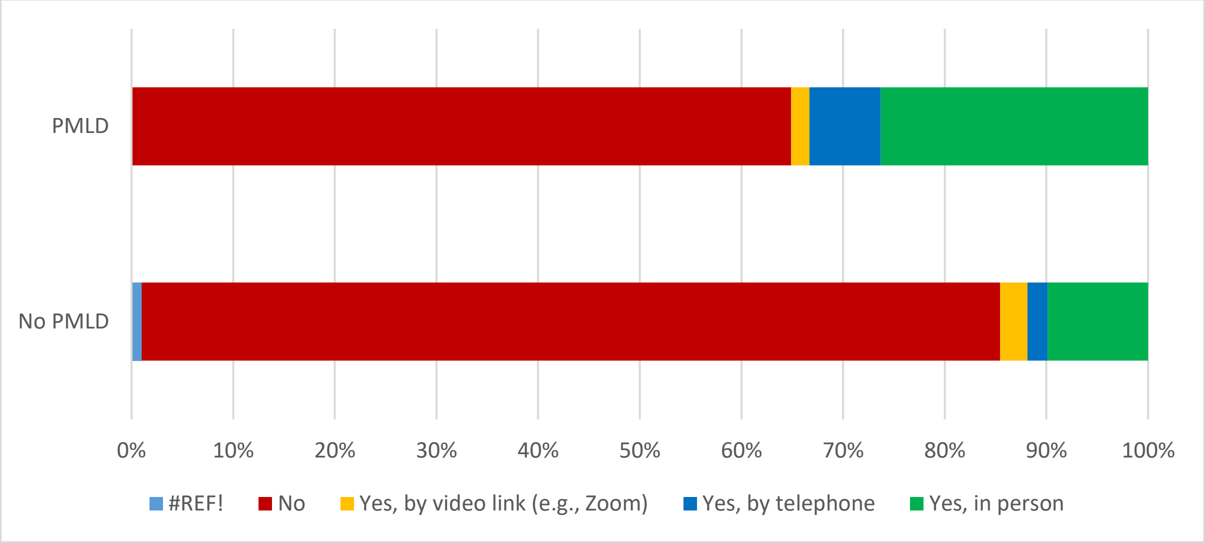

Figure 4.13. In the last four weeks has the person you support/care for been in contact with a speech and language therapist, occupational therapist, or physiotherapist? (percentage of all Cohort 2 participants with and without PMLD)

In the last four weeks, 41% of people with PMLD had had contact with their GP, most commonly by phone (21% of all people with PMLD); 34% of people without PMLD had had contact with their GP in the last four weeks, again most commonly by phone (17% of all people without PMLD).

In the last four weeks, 25% of people with PMLD and 27% of people without PMLD had had contact with a community nurse, most commonly by phone (17% of all people with PMLD; 14% of all people without PMLD).

In the last four weeks, 9% of people with PMLD and 12% of people without PMLD had had contact with a Psychiatrist, Clinical Psychologist or Counsellor. People with PMLD were mostly likely to have had contact by phone (7% of all people with PMLD), with no-one having contact in person. People without PMLD were most likely to have had contact in person (7% of all people without PMLD).

In the last four weeks, 35% of people with PMLD and 15% of people without PMLD had had contact with a speech and language therapist, occupational therapist, or physiotherapist . For people with and without PMLD, contact had been most commonly in person (26% and 10% of people respectively).

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 in the last four weeks. These data are presented in Table 4.9 for both groups.

Table 4.9. People with learning disabilities who had planned medical tests, operations or appointments been cancelled in the last four weeks

		People with PMLD	People without PMLD
Planned medical test cancelled			
	Yes	8%	9%
	No	88%	89%
	Don’t know	4%	3%
Planned medical operation cancelled			
	Yes	1%	2%
	No	99%	98%
	Don’t know	0%	0%
Planned outpatient hospital appointment cancelled			
	Yes	12%	9%
	No	85%	87%
	Don’t know	3%	3%

In the last four weeks, 8% of people with PMLD and 9% of people without PMLD had had a planned medical test cancelled. Very few people with PMLD (1%) or without PMLD (2%) had had a planned medical operation cancelled in the last four weeks. However, in the last four weeks 12% of people with PMLD and 9% of people without PMLD had had a planned outpatient hospital appointment cancelled.

We asked follow-up questions about whether people with learning disabilities were currently waiting for planned medical tests, operations and hospital appointments. These data, and information about how long they had been waiting is displayed in Table 4.10.

Table 4.10. People with learning disabilities who were waiting for a planned medical test, operation or outpatient hospital appointment

	People with PMLD	People without PMLD
Are they waiting for a planned medical test?		
Yes	26%	24%
No	71%	74%
Don't know	3%	2%
Of those waiting, how long have they been waiting for this planned medical test?		
Less than a month	10%	17%
1-2 months	20%	11%
3-6 months	23%	23%
More than 6 months	47%	49%
Are they waiting for a planned medical operation?		
Yes	6%	9%
No	94%	91%
Don't know	0%	1%
Of those waiting, how long have they been waiting for this planned medical operation?		
Less than a month	14%	15%
1-2 months	14%	8%
3-6 months	29%	23%
More than 6 months	43%	54%
Are they waiting for a planned outpatient hospital appointment?		
Yes	34%	31%
No	63%	67%
Don't know	3%	2%
Of those waiting, how long have they been waiting for this planned outpatient hospital appointment?		
Less than a month	15%	13%
1-2 months	15%	17%
3-6 months	21%	28%
More than 6 months	49%	41%

Around a quarter of people with and without PMLD (26% versus 24%) were waiting for a planned test, and around a third of people with and without PMLD (45% versus 31%) were waiting for a planned outpatient hospital appointment. Fewer people with and without PMLD (6% versus 9%) were waiting for a planned medical operation.

Over 40% of people with and without PMLD had been waiting for a test, operation or outpatient hospital appointment for more than six months.

4.3.4. Annual health checks

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). Further information about annual health checks is presented in Figure 4.14 for people with and without PMLD.

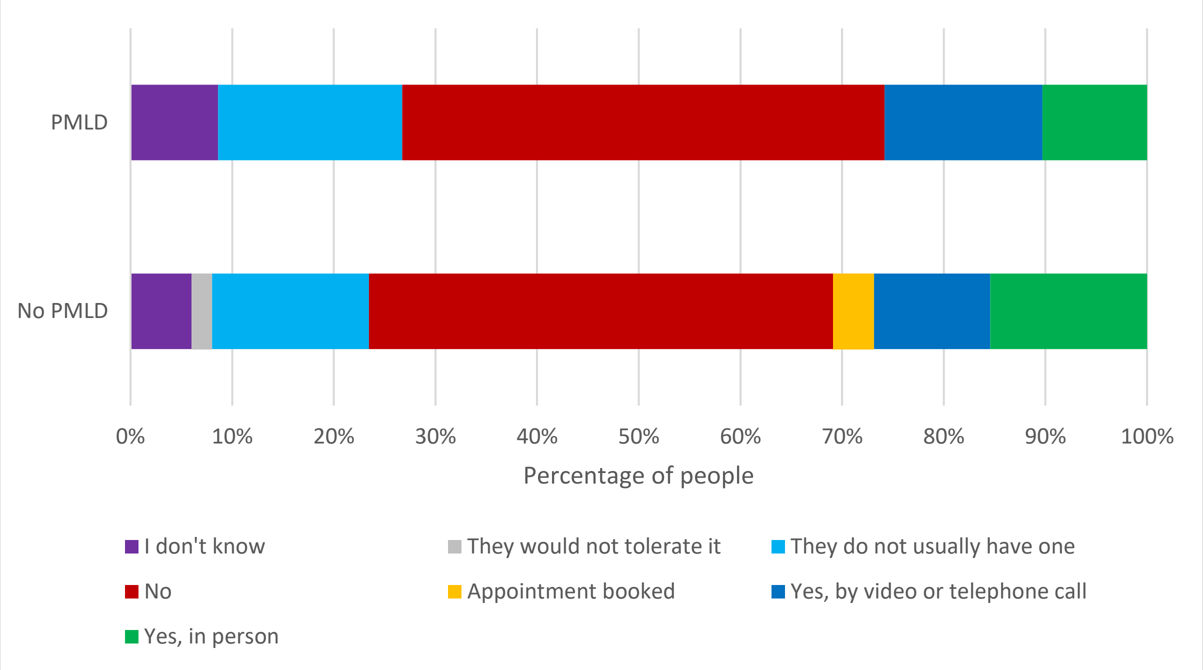

Figure 4.14. Since the start of this year (2021), has the person you support/care for had their annual health check?

Just over a quarter of people with and without PMLD (26% versus 27%) had had an annual health check since the start of the year (2021), with around half of these checks being done by phone or video link.

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 in the weeks before the survey was completed, and these data are presented in Figure 4.15.

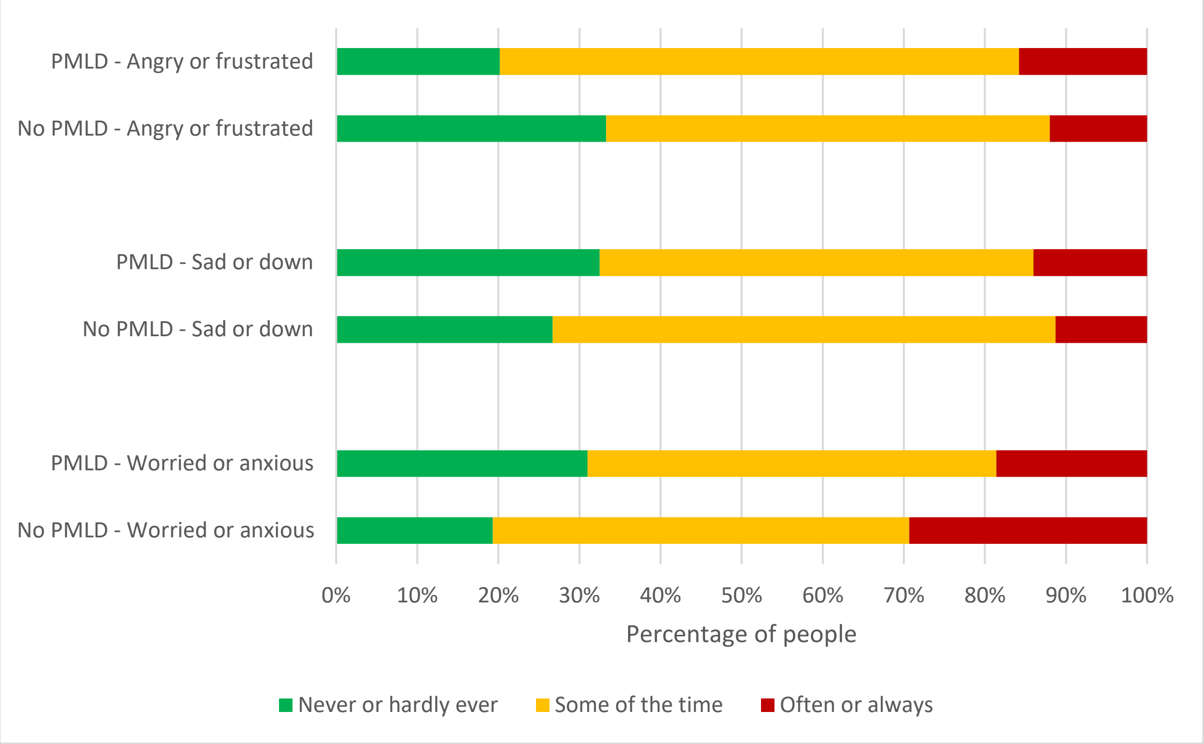

Figure 4.15. How people with learning disabilities have felt in the last four weeks

Most family carers/paid support staff of people with and without PMLD reported that the person they support/care for had felt angry or frustrated, sad or down, and worried or anxious at least some of the time in the last four weeks. Almost 30% of people without PMLD were reported to have felt worried or anxious often or always in the last four weeks.

We asked if people with learning disabilities were receiving any support when they are feeling sad, worried, or angry. These data are displayed in Table 4.11 below.

Table 4.11. Support for people with learning disabilities when they are feeling sad, worried or angry (Select all that apply)

	People with PMLD	People without PMLD
Yes, from a mental health professional	5%	12%
Yes, from someone paid to support them	37%	29%
Yes, from family	54%	65%
Yes, from friends	3%	11%
Yes, from mental health resources (online, videos, information, etc.)	1%	3%
Not applicable	25%	18%
Don’t know	3%	1%
Prefer not to say	1%	0%

For people with and without PMLD, support for people when they were feeling sad, worried or angry most commonly came from family (54% versus 65%) or someone paid to support them (37% versus 29%). Fewer people with and without PMLD got support from a mental health professional (5% versus 12%), friends (3% versus 11%) or mental health resources (1% versus 3%).

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, broken down 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,
- whether people with learning disabilities knew people who had died during the COVID-19 pandemic, and
- how people are using technology (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 in the last four weeks. 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 4.12.

Table 4.12. How people with learning disabilities stay in contact with friends, family and other people

		People with PMLD	People without PMLD
Face-to-face			
	Yes	72%	75%
	No	26%	22%
	Don’t know	3%	4%
Meet outside			
	Yes	61%	74%
	No	36%	24%
	Don’t know	3%	3%
Meet in others’ house			
	Yes	22%	38%
	No	77%	62%
	Don’t know	1%	1%
Meet in own house			
	Yes	54%	51%
	No	43%	46%
	Don’t know	3%	3%
Meet in other indoor places			
	Yes	43%	46%
	No	56%	49%
	Don’t know	2%	6%
Talk on telephone			
	Yes	28%	59%
	No	72%	40%
	Don’t know	0%	1%
Through video calls			
	Yes	48%	58%
	No	50%	39%
	Don’t know	2%	4%
Other ways (e.g., photo albums or virtual hugs)			
	Yes	19%	24%
	No	79%	67%
	Don’t know	3%	9%

For people with PMLD, the most frequently reported ways of staying in contact with family and friends were meeting face to face (72%), meeting outside (61%) and meeting in the person’s own house (54%). For people without PMLD, the most frequently reported ways of staying in contact with family and friends were meeting face to face (75%), meeting outside (74%), talking to the phone (59%), meeting through video calls (58%) and meeting in the person's own house (51%).

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 4.16 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.

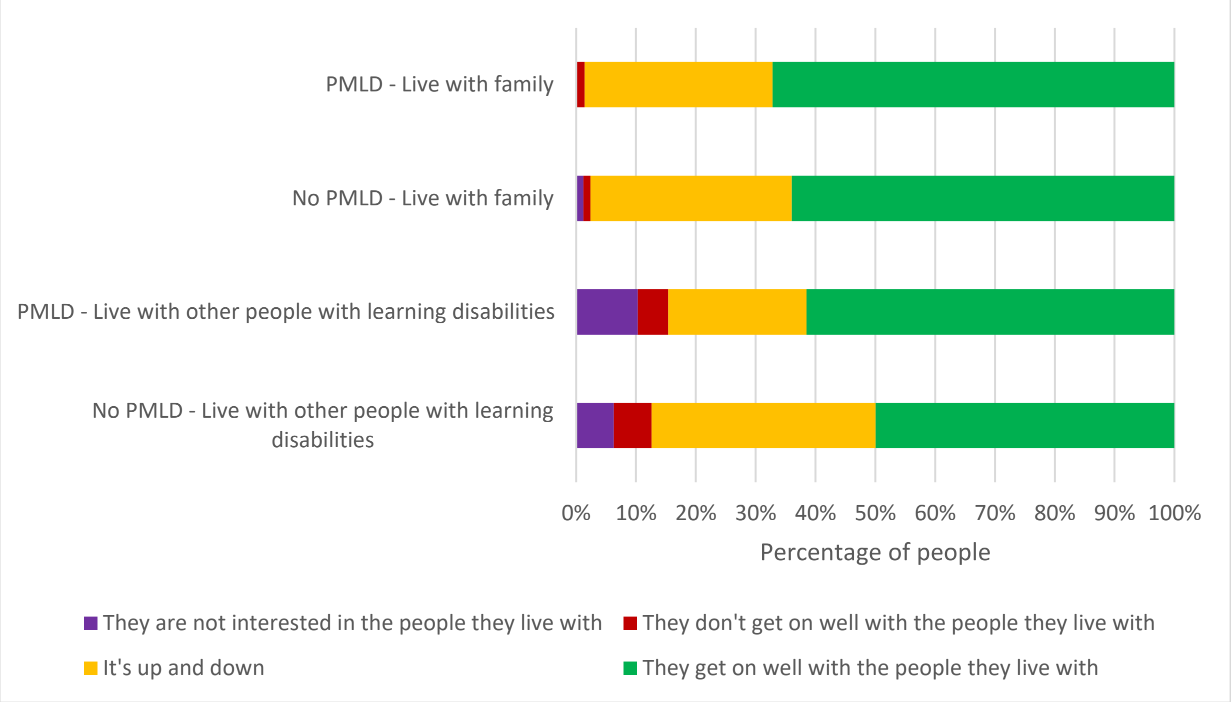

Figure 4.16. In the last four weeks, how has the person you support/care for got on with the people they live with?

Around two-thirds of people with and without PMLD living with family members were reported to get on well with the people they live with (67% and 64% respectively), with almost all the rest reported to have ups and downs in how they got on with others (31% and 34% respectively). Most people with and without PMLD living in other living situations (mainly with other people with learning disabilities, with some form of support) were also reported to get on well with others they lived with (62% and 50% respectively), although some people with and without PMLD in these other living situations were reported to not be interested or not getting on well with others they lived with (15% and 13% respectively).

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. 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 4.17.

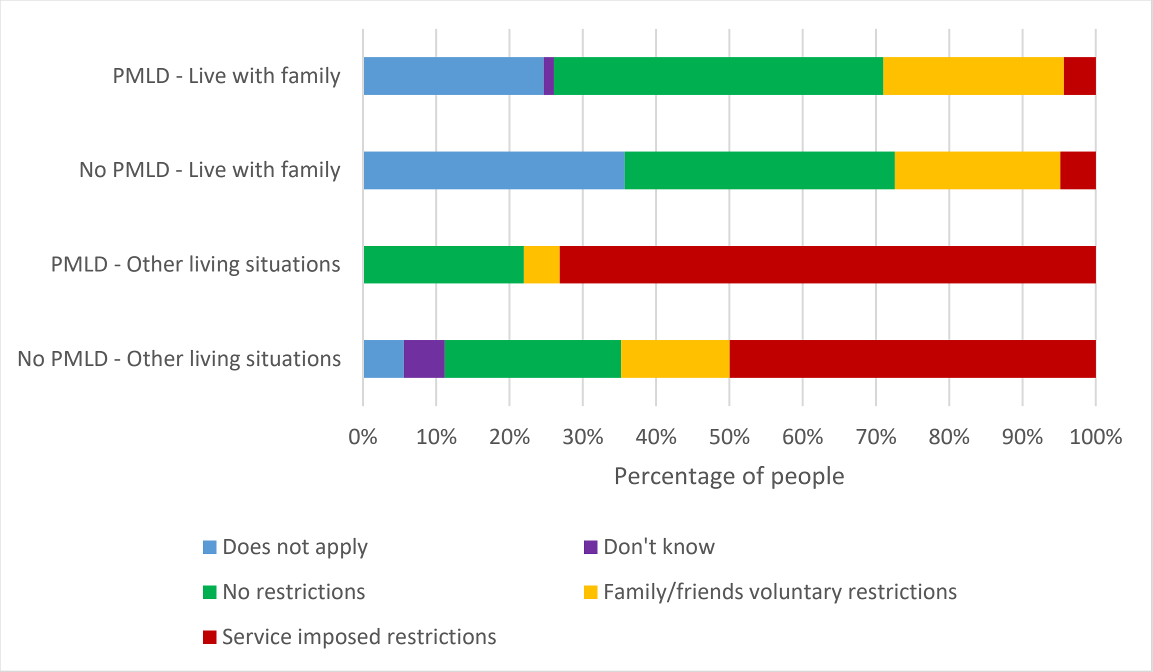

Figure 4.17. Have there been visitor restrictions to the home of the person you support/care for in the last four weeks?

For people with and without PMLD who were living with family, the most common response was that there were no restrictions on visitors (44% and 36% respectively). Very few people living with family had any restrictions on visiting the family home imposed by services (4% and 5% respectively), and for about a quarter of people family and friends were voluntarily restricting visits (24% and 22% respectively. In contrast, three quarters of people with PMLD living in other situations had restrictions on visiting their home imposed by services (75%); this was also the case for a majority of people without PMLD living in other situations (52%). For people with and without PMLD living in other situations, around a quarter of people had no restrictions on visitors (23% and 25% respectively).

We asked participants in Cohort 2 some follow-up questions about visitor restrictions, including the extent of restrictions for family and friends, and whether they had been restricted in terms of when they could leave their home. These data are presented in Table 4.13. For the question about service restrictions on when people with learning disabilities could leave home, this was only asked of people who lived in services. The question about restrictions on visits from family and friends was asked of all participants in Cohort 2, regardless of living situation.

Table 4.13. Visitor restrictions for people with learning disabilities in the last four weeks

	People with PMLD	**People without PMLD**
Service restriction on when they can leave home		
Yes – cannot leave home at all	3%	2%
Yes – have to self-isolate for at least 7 days after leaving home	2%	1%
Yes – cannot stay overnight with family or friends	4%	7%
No	49%	53%
Don’t know	3%	1%
Does not apply	40%	35%
Restrictions on visits from family and friends		
Full access	50%	50%
Restrictions on some occasions	10%	13%
Partial access	18%	25%
Only family and friends who are Key Workers	10%	2%
No access	6%	5%
Don’t know	6%	4%

Of those people with PMLD for whom this question was applicable, 19% of people had some form of restrictions imposed on them about when they were able to leave their home. Of those people without PMLD for whom this question was applicable, 18% of people with learning disabilities had some form of restrictions imposed on them about when they were able to leave their home. For both groups, the most common restriction was not being able stay with family or friends overnight.

Half of people with and without PMLD (50% in both groups) had some restrictions imposed on visits from family members and friends or professionals.

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 4.18.

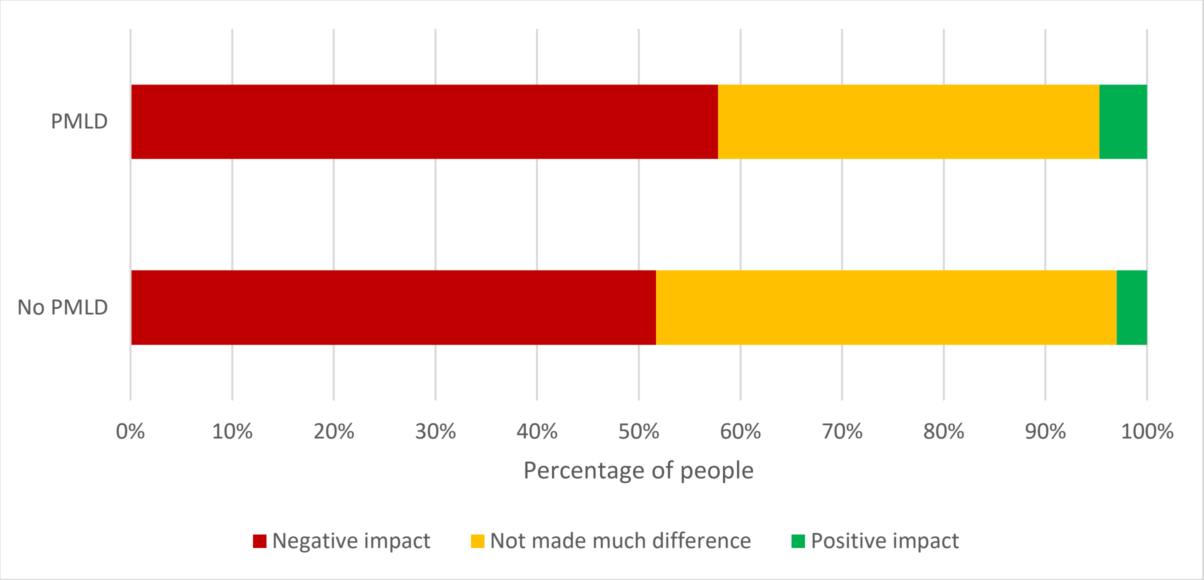

Figure 4.18. Have these restrictions on access/visits had an impact on the person you support/care for?

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 (58% and 52% respectively).

4.5.4. Deaths during the COVID-19 pandemic

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 during the COVID-19 pandemic. These data are displayed for people with and without PMLD in Cohort 2, in Figure 4.19.

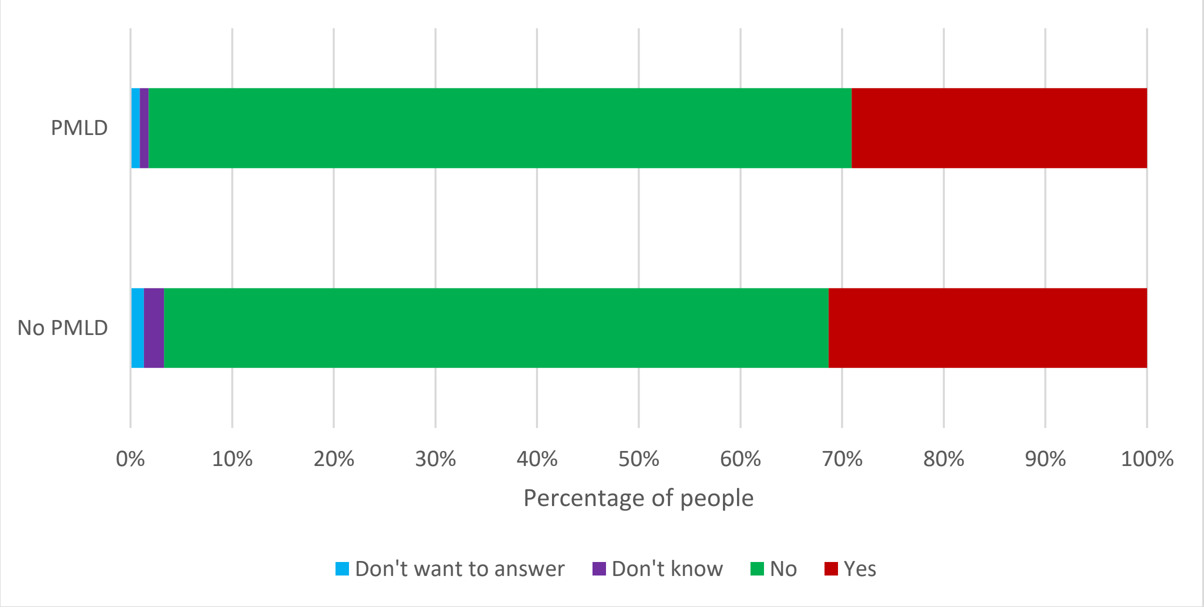

Figure 4.19. Has anyone the person you support/care for knew well or someone important to them died from any illness or any reason at all since the beginning of the COVID-19 pandemic?

A similar proportion of people with PMLD and people without PMLD have experienced someone close to them die during the COVID-19 pandemic (29% and 31% respectively).

In Wave 3 of the study, for all the people who were reported to have had someone close to them die, we asked follow-up questions about the number of people who had died, and what their relationships were to the people with learning disabilities in both cohorts. These data are presented in Table 4.14.

Table 4.14. Of the people with learning disabilities who have had someone who was known well or important to them die since the start of the COVID-19 pandemic, how many people have died?

	People with PMLD (n = 34)	People without PMLD (n = 47)
One	56%	52%
2-3	40%	45%
Four or more	4%	3%

For the 34 people with PMLD who had experienced a death of someone close to them during the COVID-19 pandemic, this was most commonly one person (17% of all people with PMLD in Cohort 2) or 2-3 people (11%), with people most commonly experiencing the death of a parent or grandparent. For the 47 people without PMLD in Cohort 2 who had experienced a death of someone close to them during the COVID-19 pandemic, this was most commonly one person (16% of all people without PMLD in Cohort 2) or 2-3 people (15%), with people most commonly experiencing the death of a grandparent, friend or parent.

When asked about how much they thought that their life had changed because those important people had died, a majority of family carers and paid support staff of people with and without PMLD reported that their life has not changed very much (58% and 53% respectively). For 30% of people with and without PMLD (30% for both groups), it was reported that the person’s life feels different in some ways but it a lot of ways life is pretty much the same. For over 10% of people with and without PMLD (12% and 17% respectively), it was reported that everything in the person’s life had changed as a result of the death.

We asked if there was anyone who could help people with learning disabilities deal with the death of the people who were important to them. These data are presented in Table 4.15.

Table 4.15. Are there people who can help the person you support/care for deal with this person's death?

	People with PMLD (n = 34)	People without PMLD (n = 47)
A counsellor is helping	3%	0%
A health professional (e.g., a psychologist, community nurse) is helping them	3%	2%
The people around them are helping them	44%	47%
There is no one to help them	12%	15%
They don't need that kind of support	38%	36%

For over a third of people with and without PMLD, family carers/support workers reported that the person didn't need support to deal with the death of the person close to them (38% and 36% respectively). The most common type of support came from those around the person (44% of 47% of all people with and without PMLD respectively); very few people were getting professional support of any kind (6% of all people with PMLD; 2% of all people without PMLD in Cohort 2).

4.5.5. 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. 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 4.16 below.

Table 4.16. Internet and telephone access and use for people with learning disabilities

	People with PMLD	People without PMLD
Internet at home	66%	80%
Device to use internet without support	14%	19%
Device to use internet with support	18%	23%
Telephone for calls	16%	52%
Telephone to be used on their behalf	31%	32%
Internet to be used on their behalf	31%	17%

Most people with PMLD (66%) were reported to have the internet at home, and were more likely to have a phone (31%) or the internet (31%) used on their behalf, rather than having a phone for making calls (16%) or a device to use the internet with (18%) or without (14%) support. A substantial majority of people without PMLD in Cohort (80%) were reported to have the internet, with most people having a phone for making calls (52%).

We also asked about what people who had the internet where they lived used it for during the data collection period (July-August 2021), and how long they usually spend on the internet for non-work-related activities. These data are displayed in Figures 4.20 and 4.21 below.

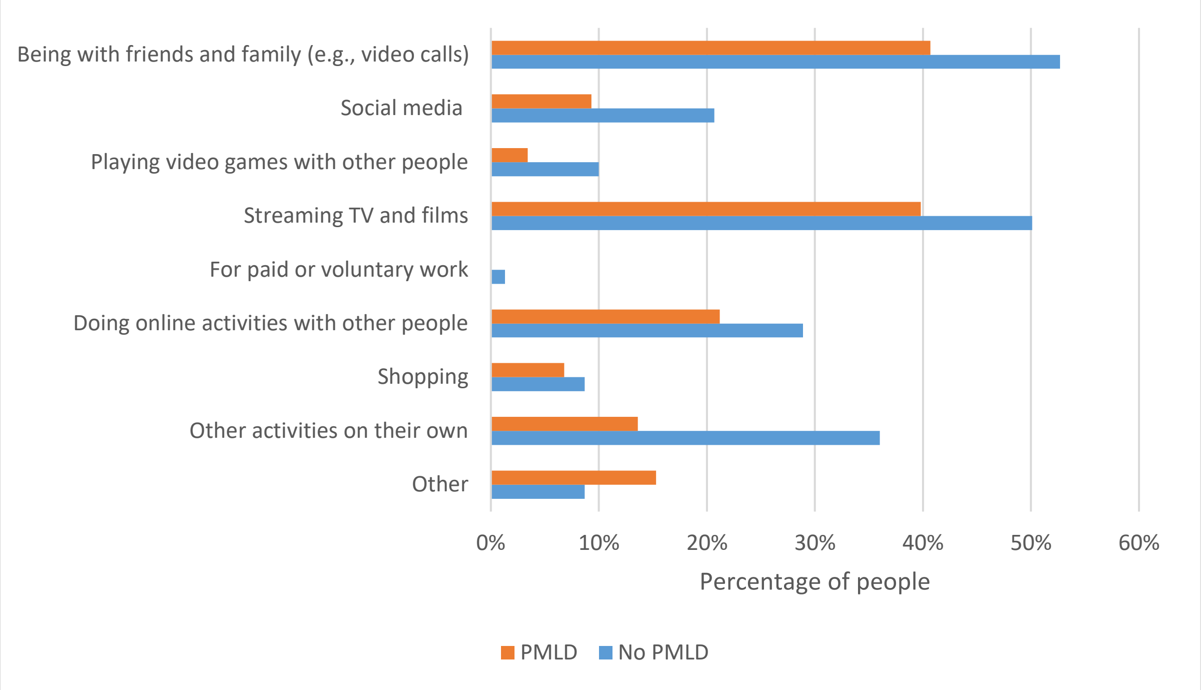

Figure 4.20. What people with learning disabilities use the internet for at the moment

The most common uses for the internet for people with PMLD were being with friends and family (e.g., video calls; 41%), streaming TV and films (40%) and doing other activities with other people (21%). For people without PMLD, the most common uses for the internet were being with friends and family (e.g., video calls; 53%), streaming television and films (50%), and doing online activities on their own (36%). Almost no-one with or without PMLD in Cohort 2 were using the internet for work or volunteering.

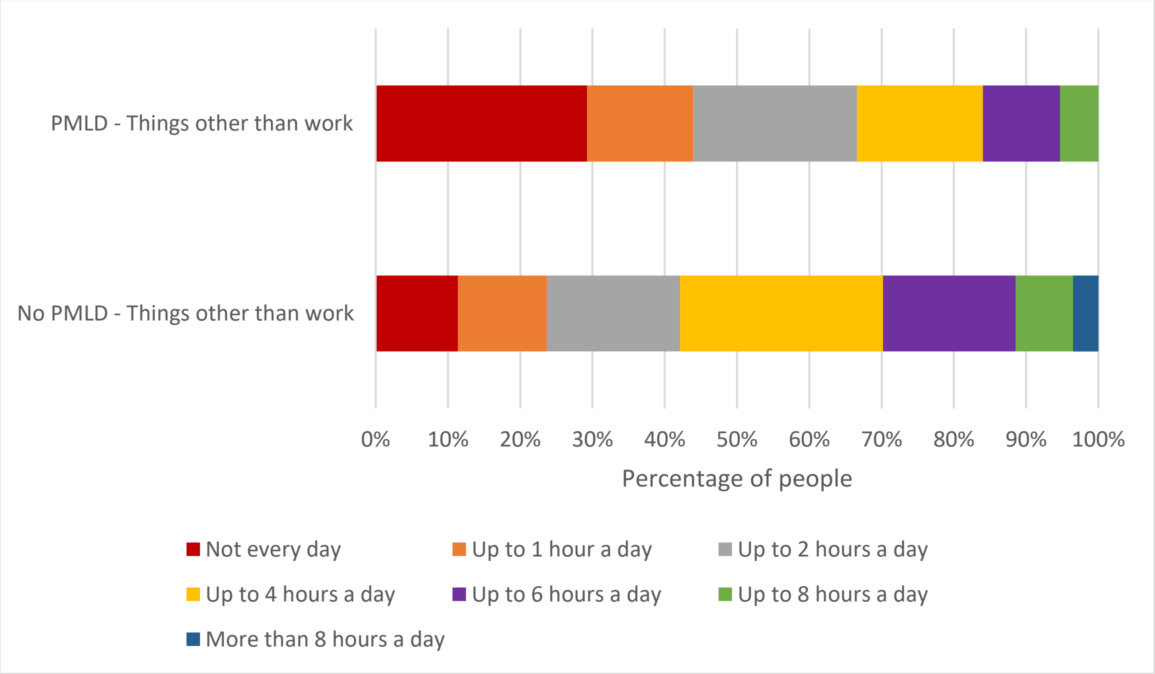

Figure 4.21. How long people with learning disabilities who used the internet would use it for each day for non-work purposes

As can be seen in Figure 4.21, among those people who used the internet, 33% of people with PMLD and 58% of people without PMLD used the internet for more than two hours per day.

Figure 4.22, below, shows how people with and without PMLD in Cohort 2 were reported to feel about taking part in online activities.

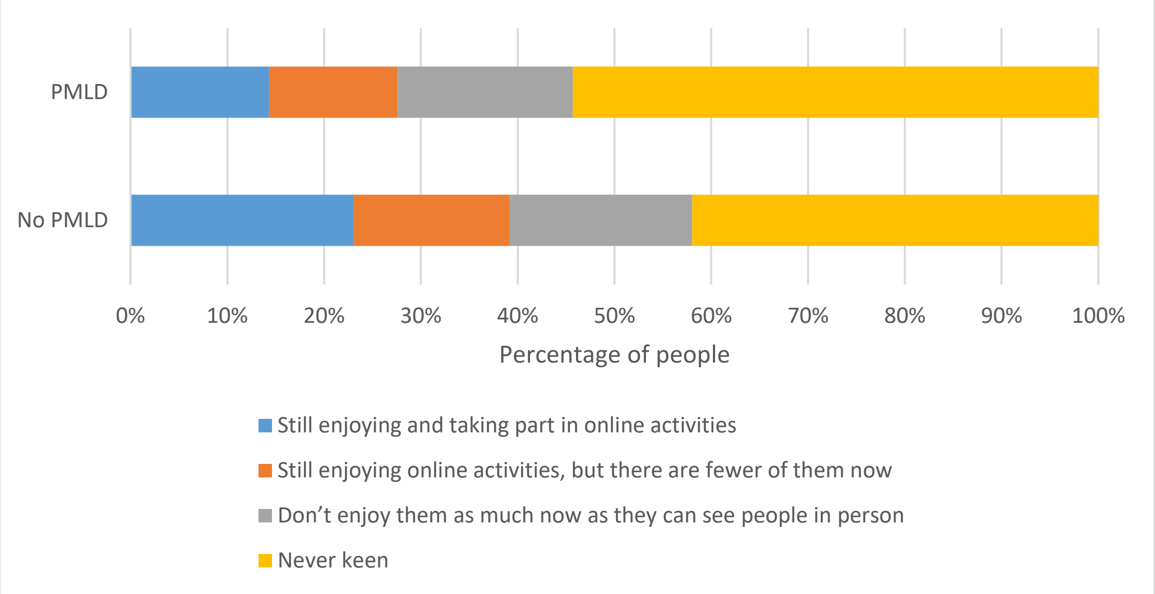

Figure 4.22. Since the early days of the pandemic in 2020, how keen has the person you support/care for been to join online activities?

The majority of people with PMLD (54%) and 42% of people without PMLD were reported to have never been keen on online activities. While many people with and without PMLD (28% versus 39%) were still enjoying online activities, some people (13% and 16% respectively) there weren't as many online activities to take part in, and some people (18% and 19% respectively) weren't enjoying online activities as much now that they could see people in real life again.

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, including:

- access to formal sources of support,
- changes to support,
- satisfaction with support, and
- personal budgets.

4.6.1. Access to support

Figure 4.23 and Table 4.17 present data about whether people in Cohort with and without PMLD had received formal sources of support in the four weeks before the survey.

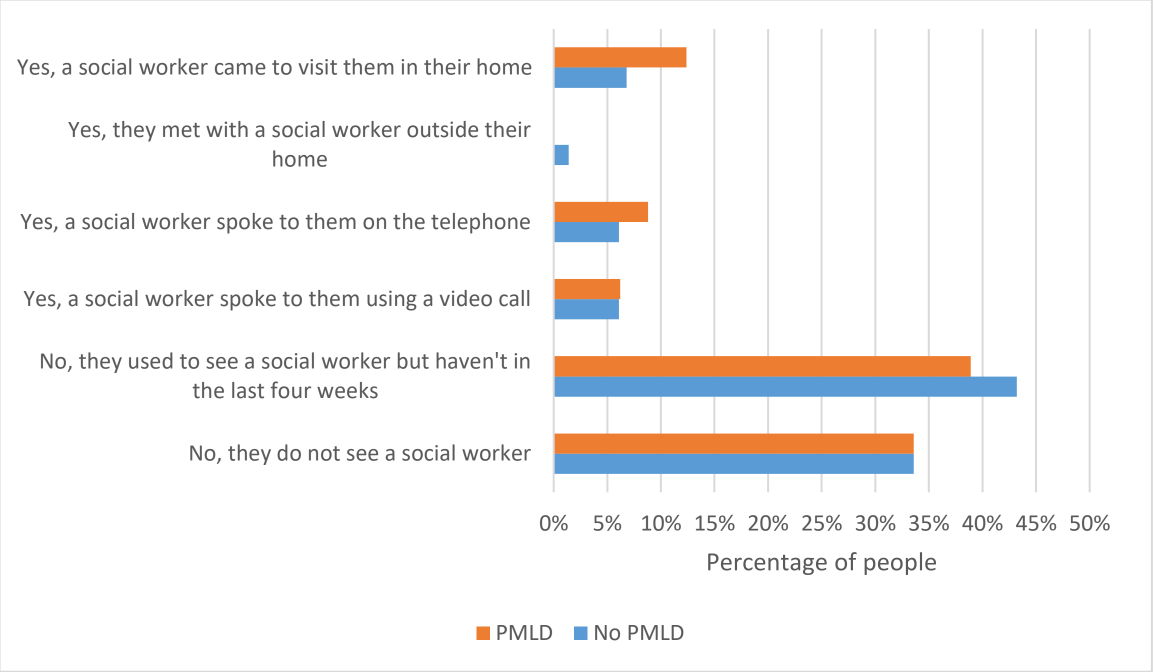

Figure 4.23. Has the person you support/care for been in contact with a social worker in the last four weeks? (Select all that apply)

Overall, 27% of people with PMLD had had some contact with their social worker in the last four weeks, with more of this contact being via phone or video (15%) rather than face to face (12%). Overall, 39% of people with PMLD used to have a social worker but hadn't been in contact with them in the last four weeks, and 34% of people did not have a social worker. Overall, 20% of people in Cohort 2 without PMLD had had some contact with their social worker in the last four weeks, with more of this contact being by phone/video (12%) rather than face to face (8%). Overall, 43% of people without PMLD used to have a social worker but hadn't been in contact with them in the last four weeks, and 37% of people did not have a social worker.

Table 4.17. Use of formal supports in the last four weeks

	People with PMLD	People without PMLD
Day service		
Yes, outside the home	29%	30%
Yes, online activities at home	1%	1%
Yes, a combination of activities outside the home and online	4%	3%
No, do not use a day service	43%	49%
No, day service is not open	17%	10%
No, day service is open but cannot/does not want to use it at the moment	8%	7%
Community activities (e.g., pub, cinema, clubs)		
Yes, outside the home	22%	30%
Yes, online activities at home	5%	6%
Yes, a combination of activities outside the home and online	10%	9%
No	63%	55%
Further education		
Yes, outside the home	5%	3%
Yes, online activities at home	0%	1%
Yes, a combination of activities outside the home and online	0%	2%
No, should be attending but have not in the last four weeks	6%	14%
Does not attend Further Education	89%	81%
Personal assistants/support workers helping at home		
Yes	68%	49%
No	4%	8%
They do not get this service	29%	43%
Going out with personal assistants/support workers		
Yes	69%	58%
No	8%	14%
They do not get this service	24%	29%
Online activities arranged by self-advocacy groups		
Yes	10%	18%
No	90%	82%
Short breaks/respite services		
Yes	12%	15%
No	88%	85%

Overall, just over half of people with and without PMLD (57% and 51% respectively) used to go to a day service. At Wave 3, a third of all people with and without PMLD had gone to their day service in the last four weeks (33% of both groups), with online activities organised by day services now rare (5% versus 4%). For 17% of people with PMLD and 10% of people without PMLD, their day service had not re-opened, and a minority of people with and without PMLD (8% versus 7%) were going to day services that were open but that they could or did not want to use at the moment.

A majority of people with and without PMLD (63% versus 55%) had not been doing service-supported community activities in the four weeks before the survey. Community activities outside people's homes (32% of people with PMLD; 39% of people without PMLD) were more common than online community activities (16% of people with PMLD; 15% of people without PMLD).

The vast majority of people with and without PMLD (89% and 81% respectively) were not attending any form of further education; 6% of people with PMLD and 14% of people without PMLD were supposed to be going to further education but had not done anything in person or online in the last four weeks.

More people with PMLD (68%) than people without PMLD (49%) had had personal assistants or support workers helping them at home in the last four weeks; fewer people used to get this support but had not had it in the last four weeks (4% of people with PMLD; 8% of people without PMLD).

More people with PMLD (69%) than people without PMLD (58%) had gone out of the house with a personal assistant or support worker in the last four weeks; 8% of people with PMLD and 14% of people without PMLD used to do this but had not done so in the last four weeks.

Fewer people with PMLD (10%) than people without PMLD in Cohort 2 (18%) had been involved in online activities organised by self-advocacy groups in the last four weeks.

Overall, 12% of people with PMLD and 15% of people without PMLD had gone to a short break or respite service in the last four weeks.

We also asked participants in Cohort 2 about how many days in the last four weeks the person they support/care for had been to day services, community activities, had personal assistants or support workers helping at home, or had been out with personal assistants or support workers, if they had accessed these formal supports. These data are displayed in Figure 4.24.

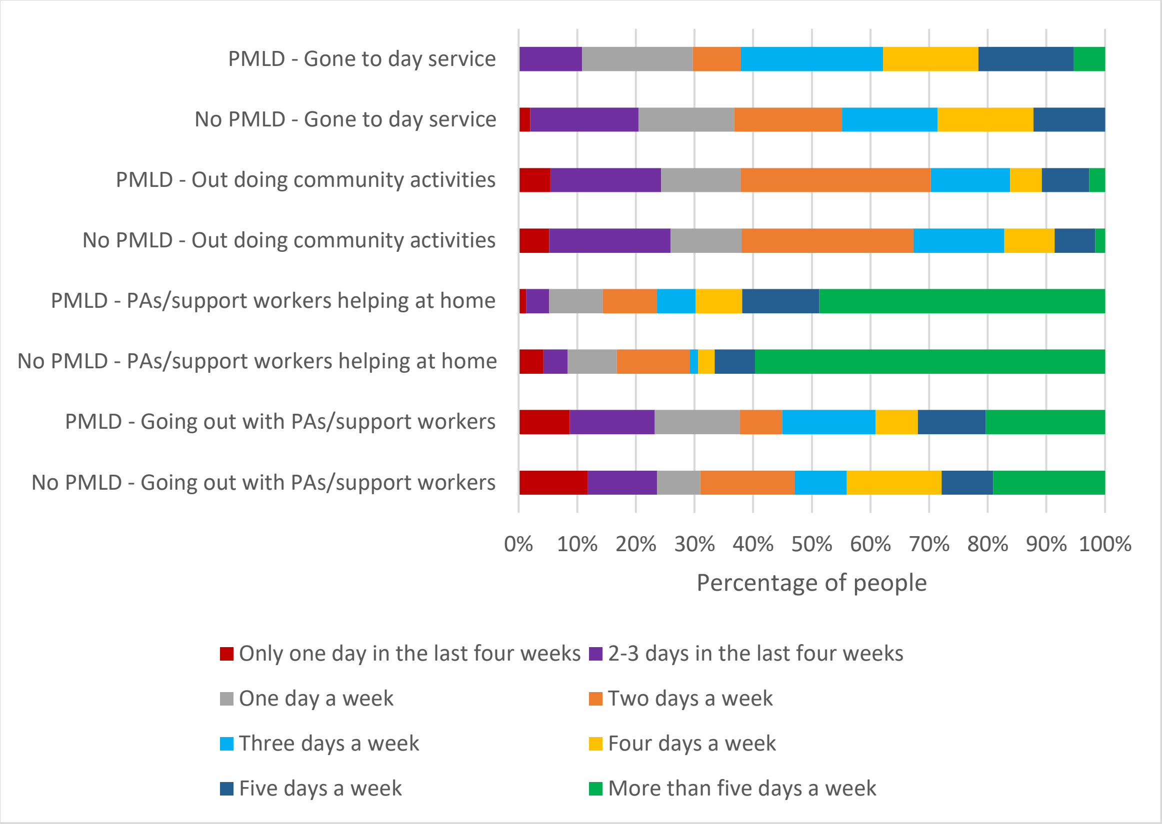

Figure 4.24. Number of days in the last four weeks that people with learning disabilities have accessed formal supports

Of those people going to day services, more people with PMLD (38%) than people without PMLD (29%) went to a day service four days or more per week in the last four weeks. Fewer people with PMLD (38%) than people without PMLD (55%) went to a day service for two days or less per week.

Of those people out doing community activities, a minority of people with and without PMLD went out for four days or more per week in the last four weeks (16% versus 17%); most people with and without PMLD (70% vs 67%) went out doing community activities two days or less per week.

Of those people with personal assistants or support workers helping the person’s home, a majority of people with and without PMLD (70% versus 69%) had support at home for four days or more per week in the last four weeks; a substantial minority (24% of people with PMLD; 29% of people without PMLD) had support at home for two days or less per week.

Of those people going out of the house with personal assistants (PAs) or support workers, 39% of people with PMLD and 44% of people without PMLD went out with PAs or support workers for four days or more per week in the last four weeks; 45% of people with PMLD and 47% of people without PMLD went out with PAs or support workers for two days or less per week.

4.6.2. Changes to and satisfaction with support

We also asked participants about any changes to support since before the COVID-19 pandemic. These data are displayed in Table 4.18.

Table 4.18. Changes to support since before the COVID-19 pandemic

	People with PMLD	People without PMLD
Support now vs. pre-pandemic		
More support now	5%	5%
About the same	36%	41%
Less support now	56%	44%
Does not get services	4%	10%
Going out to services and people supporting them now vs. pre-pandemic		
Go out for these more now	2%	5%
About the same	17%	24%
Go out for these less now	59%	51%
Does not apply	23%	20%
Online services at home		
More online services/contact now	24%	23%
About the same	17%	18%
Less online services/contact now	5%	7%
Not offered online services/contact	43%	40%
Have refused online services/contact	11%	11%

In terms of support generally, 36% of people with PMLD and 41% of people without PMLD were reported to have the same amount of support now compared to before the COVID-19 pandemic. Many more people (56% of people with PMLD; 44% of people without PMLD) were reported to be getting less support now than were reported to be getting more support now (5% of people with and without PMLD). A minority of people (4% of people with PMLD; 10% of people without PMLD) were reported to not be getting any services.

People with and without PMLD were most commonly reported to be spending less time with support workers/PAs and at services out of the house now compared to before the pandemic (59% of people with PMLD; 51% of people without PMLD), with few people going out more than before (2% of people with PMLD; 5% of people without PMLD). In terms of online services, almost a quarter reported online services at home happening more than before the COVID-19 pandemic (24% versus 23%). However, many more people with and without PMLD were reported to have not been offered online services (43% versus 40%), and further 11% of people with and without PMLD had refused online services/contact that had been offered.

The next question was only asked of the 91 people with PMLD and 93 people without PMLD where their services or support had changed. When asked if people were informed about their services changing, 52% of people with PMLD and 48% without PMLD were reported to have been informed about the changes, with more people being told (35% of people with PMLD; 42% of people without PMLD) than asked (17% of people with PMLD; 7% of people without PMLD) about the changes. These data are presented in more detail in Figure 4.25.

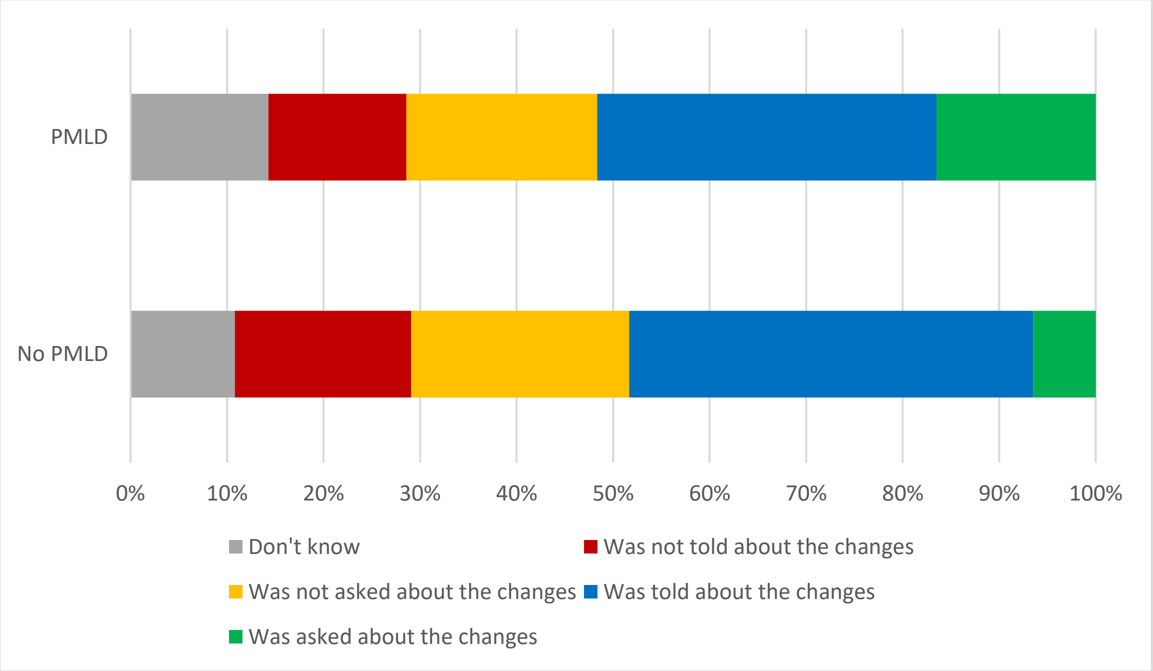

Figure 4.25. Were you or the person you support/care for asked if they wanted their service to change or told how they were going to change?

We also asked about whether people with learning disabilities were happy with the services and supports they have now, and these data are displayed in Figure 4.26.

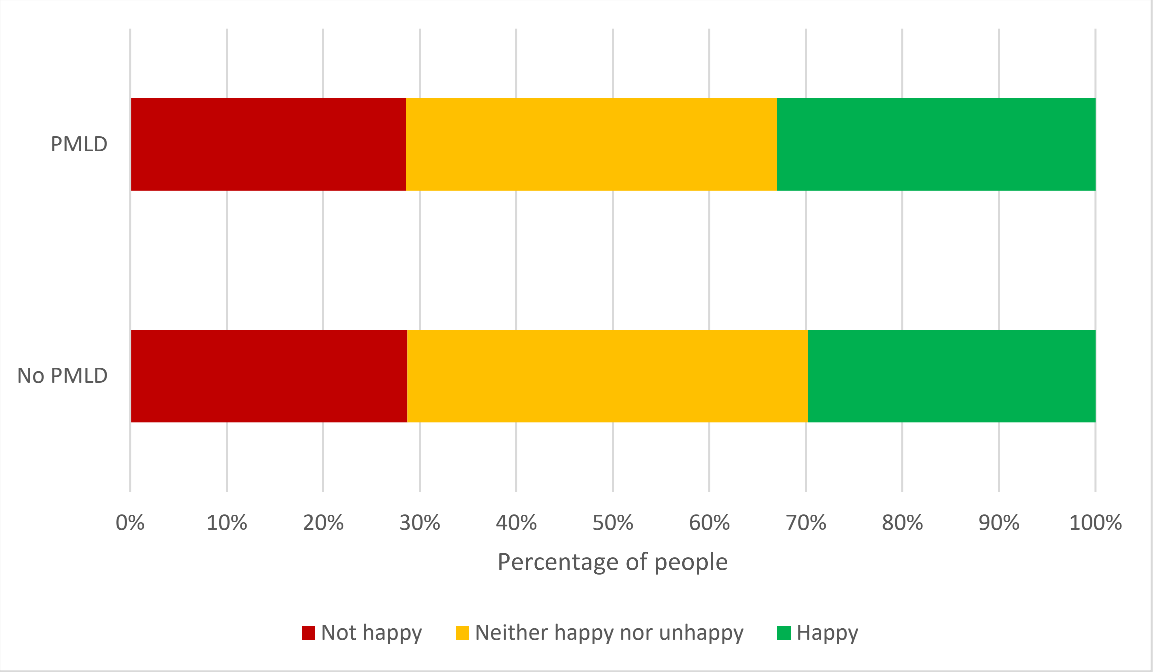

Figure 4.26. Is the person you support/care for happy with the services and support they have now?

Approximately equal numbers of people with and without PMLD were reported to be happy with the services and support they have now (33% and 30% respectively) compared to those who were not happy (29% in both groups).

4.6.3. Personal budgets

For people with PMLD, 44% of all family carers and paid support staff reported knowing roughly how much money the person they support/care for gets for services and supports, compared to 49% of all family carers and paid support staff of people without PMLD. Some people with learning disabilities in both groups were not receiving any services (9% and 13% respectively). Further detail about personal budgets is presented in Figure 4.27 and Table 4.19 below.

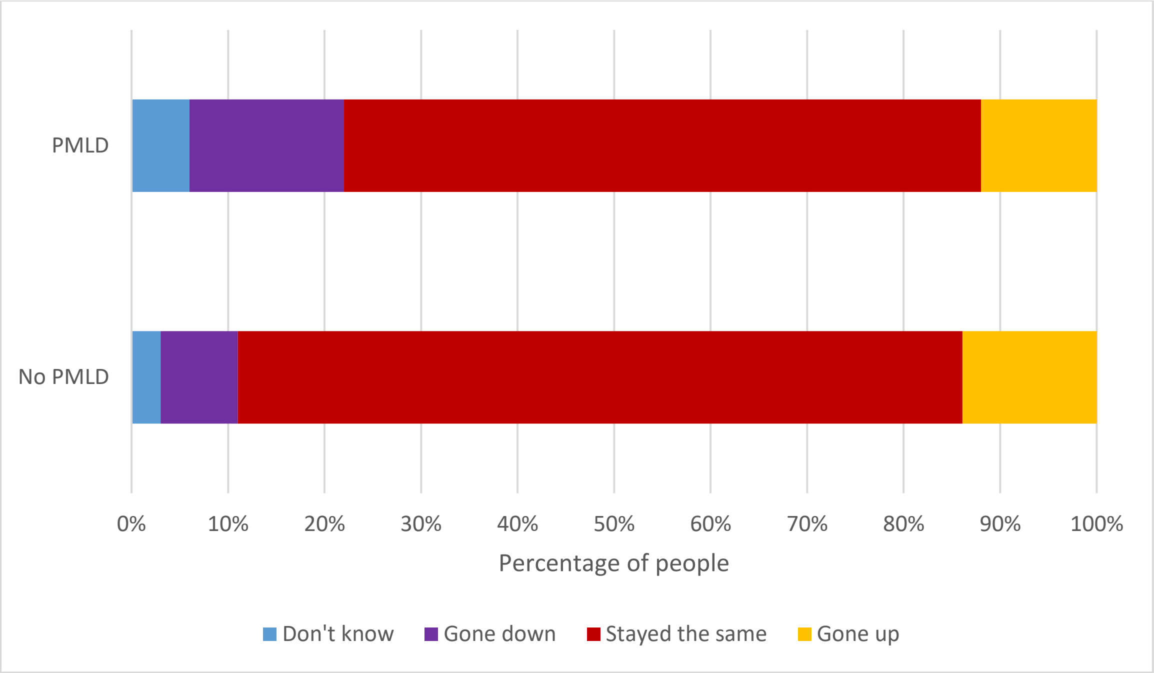

Figure 4.27. Has the amount of money the person you support/care for gets gone up or down in the last year?

For the majority of people with and without PMLD the amount of money the person gets for support/care had stayed the same in the last year (66% and 75% respectively), with smaller numbers reporting money increasing (12% and 14% respectively) and decreasing (16% and 8% respectively).

Table 4.19. Money for services and supports for people with learning disabilities

	People with PMLD	People without PMLD
Money being used for services that are not currently being received		
Yes	47%	34%
No	47%	55%
Don't know	6%	11%
Services and supports have become more expensive		
Yes	31%	26%
No	37%	47%
Don't know	31%	26%
Person with learning disabilities or family members pay for services		
Yes	40%	46%
No	51%	45%
Don't know	10%	9%

The questions on money being used for services that are not being received and services and supports becoming more expensive were answered by 51 family carers and support workers of people with PMLD and 72 family carers and support workers of people without PMLD. More people with PMLD than people without PMLD (47% versus 34%) were reported to be using money for services not currently being received. Services and supports for similar proportions of people with and without PMLD (31% and 26% respectively) were reported to have become more expensive.

All family carers and support workers answered the question on people with learning disabilities or family members paying for some services out of their own pocket. Substantial numbers of people with and without PMLD (40% and 46% respectively) were reported to be paying for at least some services out of their own of their families' pockets.

4.7. Living circumstances, employment, and money

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

- how people are getting food,
- how people are getting their medications,
- about the reasons why people with learning disabilities are leaving their homes,
- about people’s employment,
- about people’s finances, and
- about people’s neighbourhoods

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 4.20, broken down by whether the people with learning disabilities had PMLD or not.

Table 4.20. How is the person you support/care for getting food? (Select all that apply)

	People with PMLD	People without PMLD
Family is getting food for them	56%	62%
Community support project	1%	0%
From the place they live in	25%	19%
Shopping with support/care worker	9%	22%
Delivered from supermarkets	13%	15%
From other people	2%	2%
From a food bank	1%	0%
Food parcels – they are shielding	0%	1%
Finding it very difficult to get food	1%	0%

For people with PMLD, the most commonly reporting ways of the person getting food were through families getting food for them (56%), from the place they were living in (25%) and delivered from supermarkets (13%). For people without PMLD in Cohort 2, the most common ways of getting food were through their family getting food for them (62%), the person shopping for food with a support worker (22%), from the place they were living in (19%) and delivered from supermarkets (15%). Virtually no-one was reported to be finding it very difficult to get food.

4.7.2. Medications

Family carers/paid support staff reported that 84% of people with PMLD and 76% of people without PMLD were taking medications. Table 4.21 displays data about how they were getting their medicines.

Table 4.21. Does the person you support/care for need medicines at the moment? (Select all that apply)

	People with PMLD	People without PMLD
From family	42%	41%
Through a community support project	1%	0%
Delivered from pharmacy/chemist	19%	14%
From the place they are living in	16%	11%
On own with support from pharmacy/chemist	7%	13%
From friends/neighbours	1%	1%
Finding it difficult	16%	5%
Not getting medicines	0%	0%

People with and without PMLD were most likely to get their medicines through their families getting their medicines for them (42% and 41% respectively). Although no-one was not getting the medicines they needed, for 16% of people with PMLD and 5% of people without MLD it was difficult to find the medicines people needed.

4.7.3. Leaving the house

We asked about the reasons people with learning disabilities left their home during the week before the survey. The reasons people with learning disabilities left their houses are presented in Figure 4.28.

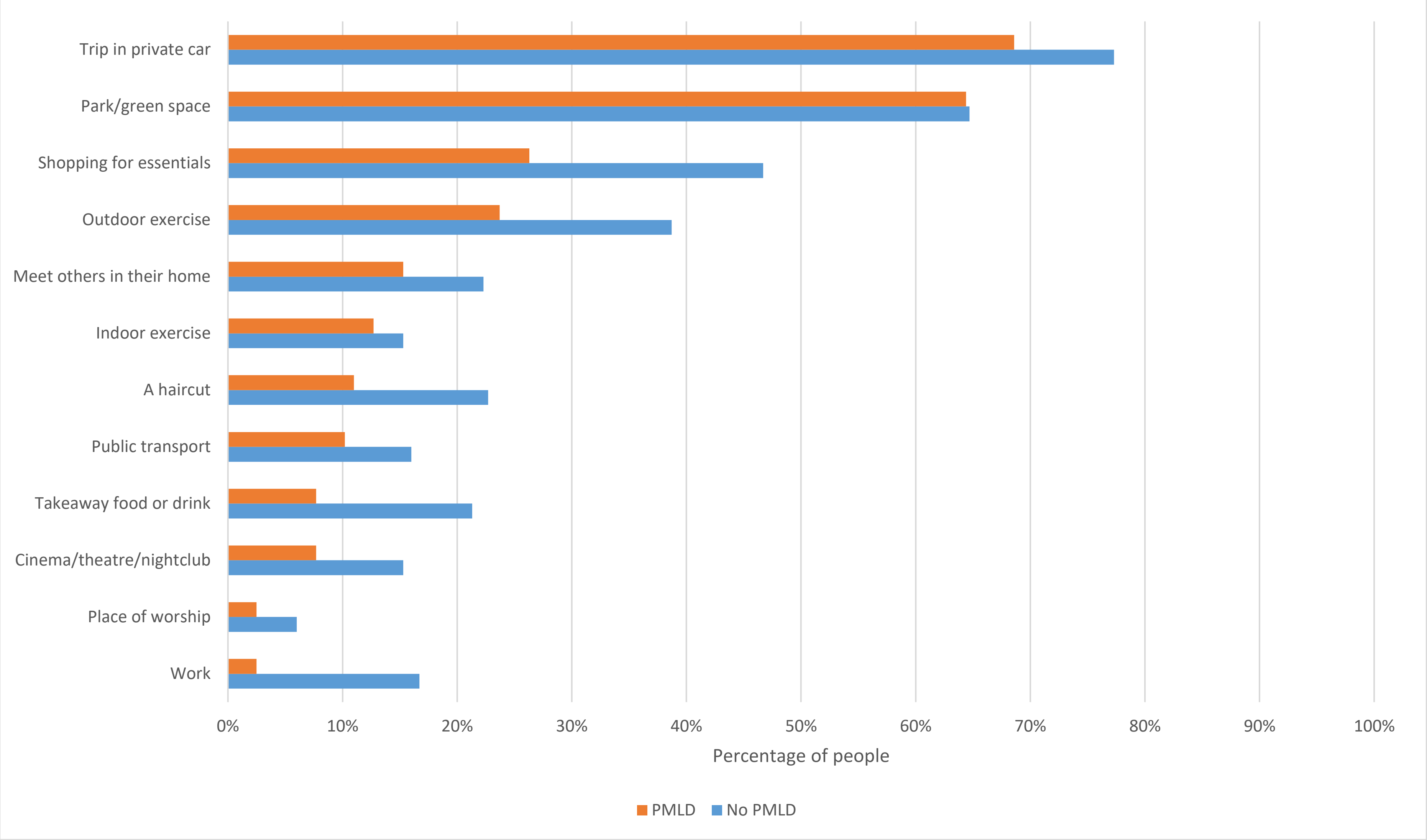

Figure 4.28. Reasons that people with learning disabilities left their house in the last week

For all the reasons to have left the house in the last week listed in Figure 4.28, people with PMLD were less likely to have left the house than people without PMLD. For people with PMLD, the most frequently reported reasons for people leaving the house were to take a trip in a private car (69%) and go to a park or green space (64%). The most frequently reported reasons for people without PMLD leaving the house were similar (77% taking a trip in a private car; 65% going to a park or green space), although substantial numbers of people without PMLD were also going out to shop for essentials (47%) and take outdoor exercise (39%).

We also asked participants whether the person they support/care for had returned to everywhere they used to go before the COVID-19 pandemic. These data are presented in Figure 4.29 below.

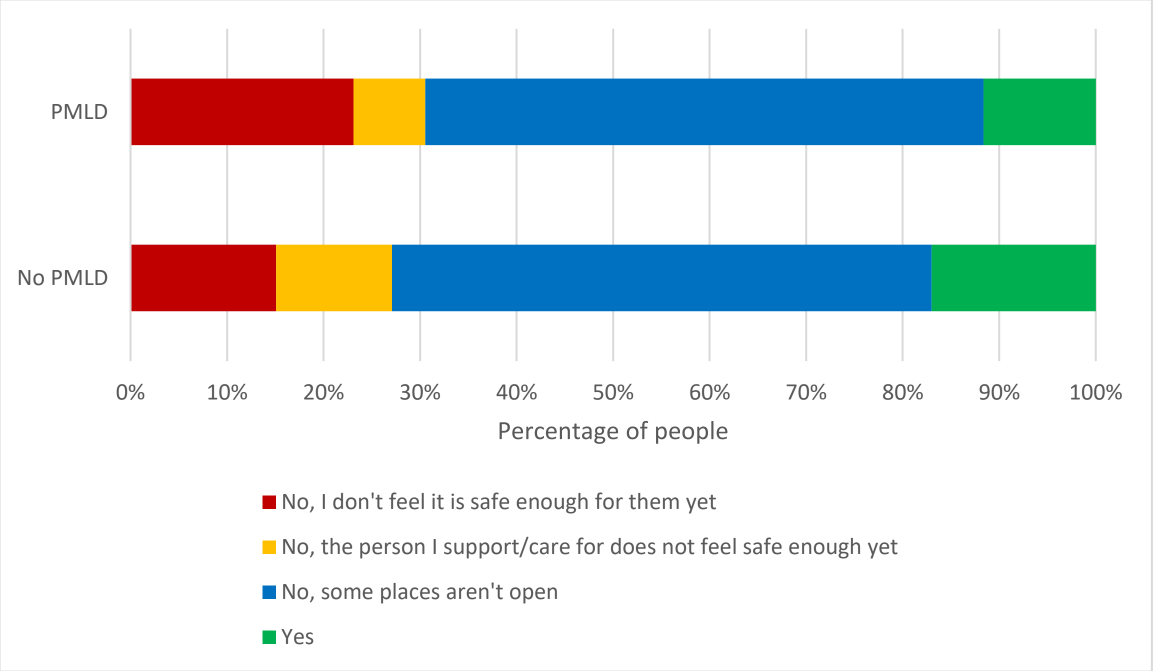

Figure 4.29. Has the person you support/care for returned to everywhere they used to go to before the COVID-19 pandemic? (Select all that apply)

Fewer people with PMLD (12%) than people without PMLD (18%) had returned to everywhere they used to go before the pandemic. The most common reason for this for both groups was that some places were not open yet (59% in both groups). For people with PMLD, they were reported to be less likely than people without PMLD to not feel safe to go back to places yet (8% versus 13%), but family carers or support workers of people with PMLD rather than people without PMLD were more likely to feel that places weren't safe for the person to go back to yet (24% versus 16%).

We also asked about what would help people with and without PMLD to feel safe enough to return, and these data are displayed in Figure 4.30 below.

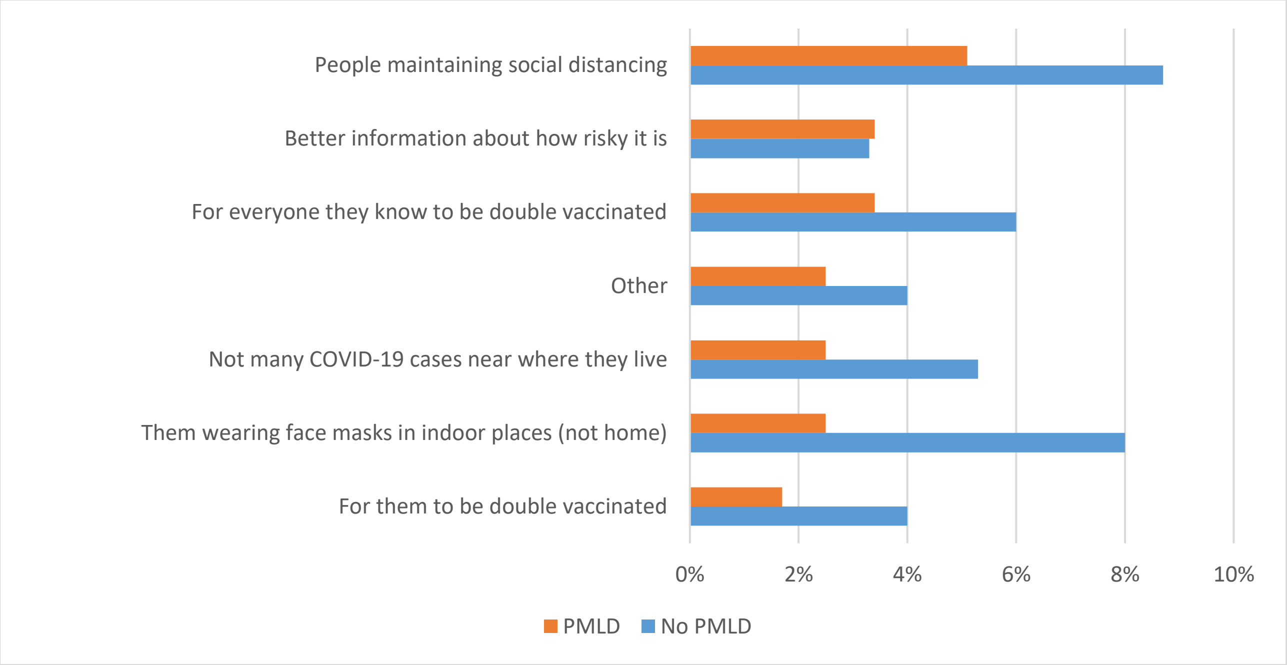

Figure 4.30. What would be needed for people with learning disabilities to feel safe to return to all the places they used to go before the COVID-19 pandemic.

Fewer than 10% of family carers or support workers of people with and without PMLD reported that any of the actions in the list in Figure 4.30 would make it safe for people with learning disabilities to go to all the places they went before the pandemic.

4.7.4. Local neighbourhoods

We asked participants in Cohort 2 about whether the person they support/care for had become friendly with the people near where they live. These data are presented in Figure 4.31 below.

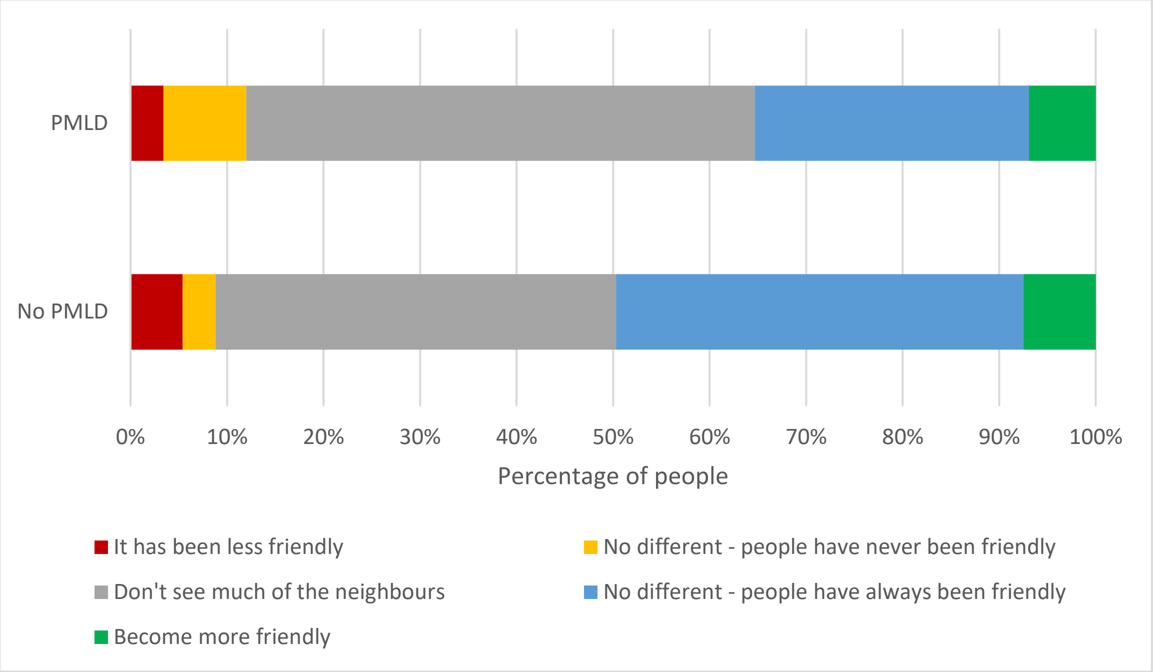

Figure 4.31. How friendly people with learning disabilities were with the people they live near

Relatively small numbers of people with and without PMLD were reported to have become more friendly with people in their neighbourhood since the start of the pandemic (7% and 8% respectively), or to have become less friendly (3% and 5% respectively). People with PMLD were most commonly reported to not see much of their neighbours (53% versus 42% of people without PMLD), and to have always been friendly with people living nearby (28% versus 42% of people without PMLD).

4.7.5. Employment

Family carers/paid support staff reported that no-one with PMLD had a paid job; 6% of people without PMLD were reported to have a paid job at the moment and a further 1% of people were furloughed. These data are presented in Table 4.22.

Table 4.22. Employment of people with learning disabilities

	People with PMLD	People without PMLD
Paid job at the moment		
Yes	0%	6%
Furloughed from job	0%	1%
Not working, but job being held open	0%	0%
No	100%	93%

We also asked about volunteer work and Table 4.23 presents data about this.

Table 4.23. Current volunteer work

	People with PMLD	People without PMLD
Volunteer job at the moment		
Yes	4%	14%
Not at the moment, but job is being held open	1%	5%
No	95%	81%

Fewer people with PMLD than people without PMLD were doing volunteer work at the moment (4% versus 14%), or had their volunteer job being held open for them (1% versus 5%).

4.7.6. 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 enough money at the moment, 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 4.32-4.34.

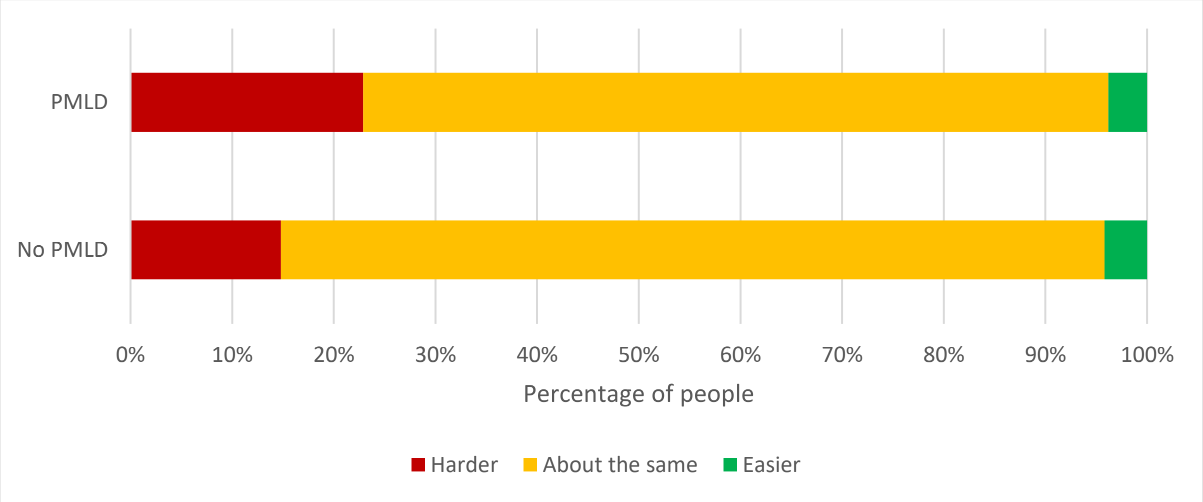

Figure 4.32. Has it been easier or harder for the household bills to be paid where the person you support/care for lives than before the start of the first lockdown in March 2020?

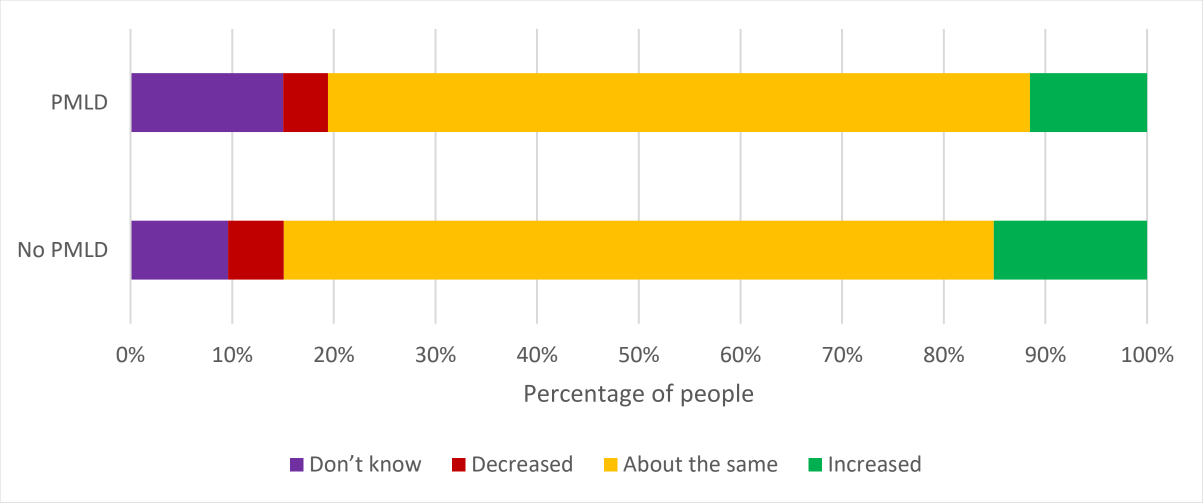

Figure 4.33. Has the amount of benefits the person you support/care for get changed the start of the first lockdown in March 2020?

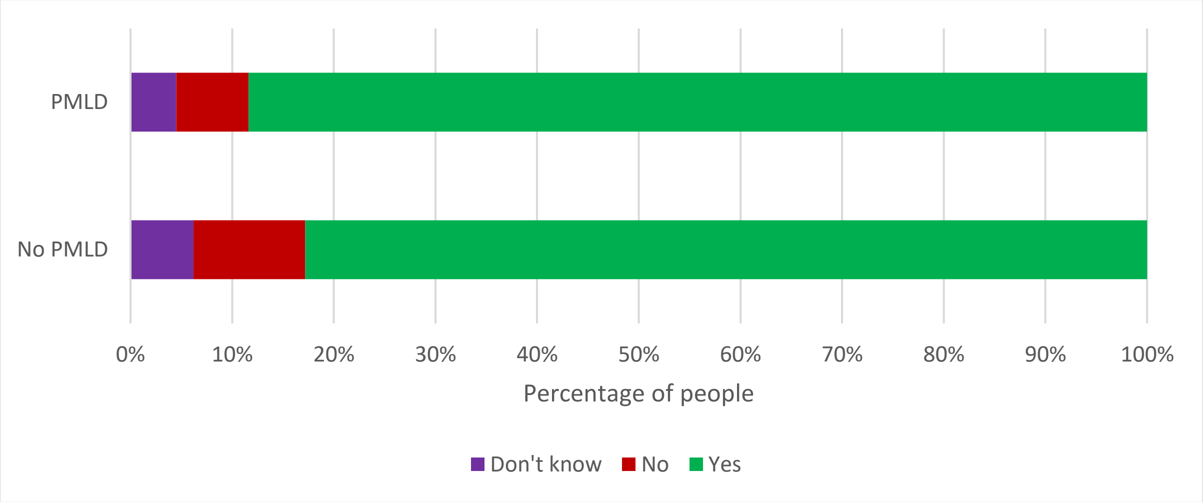

Figure 4.34. Does the person you support/care for have enough money at the moment?

Overall, 23% of family carers and support workers of people with PMLD reported that it had become harder to pay the household bills where the person lives compared to before the pandemic, compared to 15% of family carers or support workers of people without PMLD. For most people with and without PMLD, this had not changed since the start of the pandemic (73% and 81% respectively).

Regarding benefits, slightly more family carers and support workers reported that the benefits for people with and without PMLD had increased since the start of pandemic (12% and 15% respectively) rather than decreased (5% and 6% respectively). For most people levels of benefits had stayed the same since the start of the pandemic (69 of people with PMLD; 70% of people without PMLD).

A substantial majority of family carers and support workers for people with and without PMLD reported that the person they cared for/supported had enough money at the moment (88% and 83% respectively).

4.8. Future considerations

In both cohorts, we asked some open-ended questions about the lives of people with learning disabilities in the near future, including:

- how long it would be until their lives went back to how it was before the pandemic,
- what supports would be needed in case of another lockdown, and
- whether they had a holiday planned.

4.8.1. Life returning to how it was before the pandemic

Figure 4.35 displays the data about when family carers and support workers of people with and without PMLD estimate that people's lives will return to how they were before the pandemic.

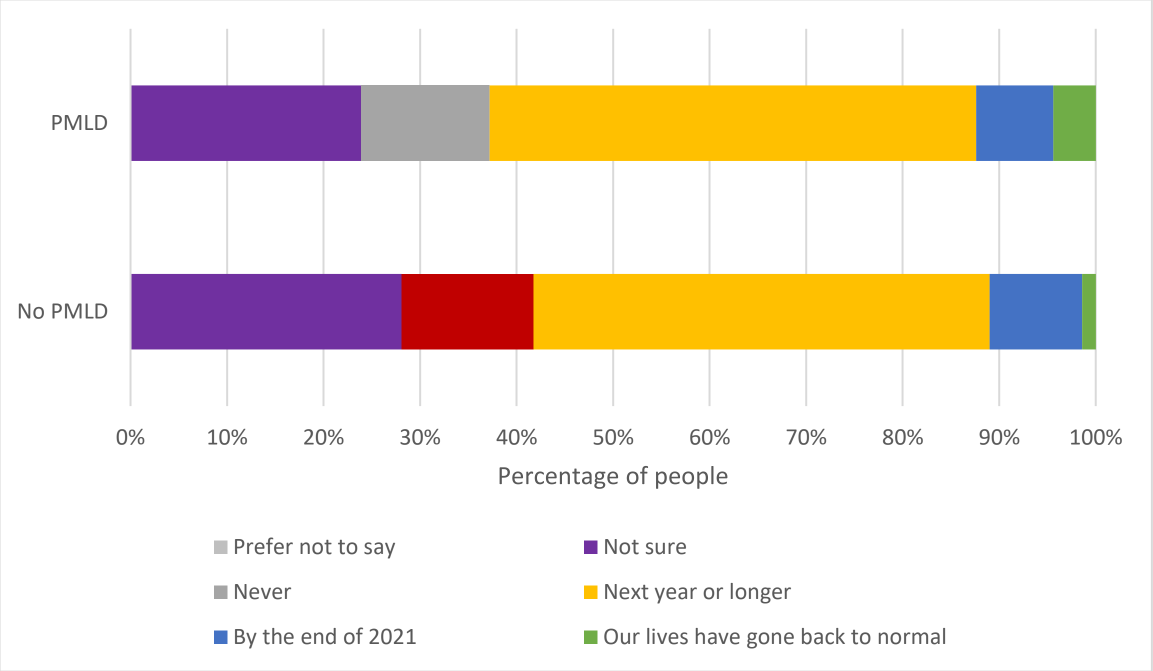

Figure 4.35. How long do you think it will be before your life/the life of the person you support/care for returns to how it was before the COVID-19 pandemic?

A very small number of people with and without PMLD were reported to have lives that had returned to normal (4% and 1% respectively). For relatively few people, family carers and support workers reported that people's lives would go back to normal by the end of 2021 (8% and 10% respectively); for most people going back to normal was reported to happen in 2022 or longer (50% and 47% respectively). A minority of family carer and support workers said the person's life would never go back to how it was (13% and 14% respectively). For around a quarter of people with and without PMLD (24% and 28% respectively), family carers and support workers were unsure when or if the person's life would go back to how it was.

4.8.2. Future lockdown planning

Participants were asked what support would be needed for the person they support, should there be another lockdown. These data are displayed in Figure 4.36.

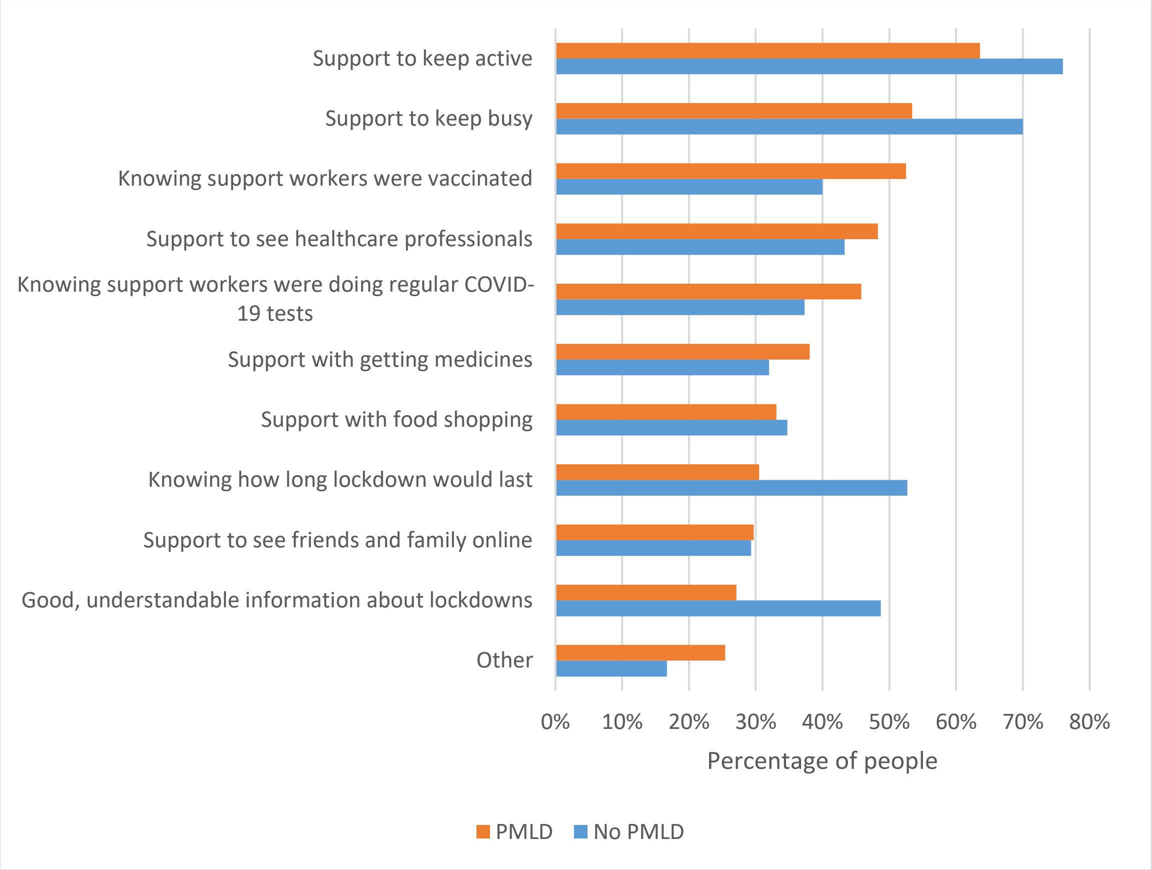

Figure 4.36. Support needed to make a future lockdown easier for people with learning disabilities

For people with PMLD, the most frequently reported things that would be needed to make a future lockdown easier would be support to keep active (64%), support to keep busy (53%) and knowing support workers were vaccinated (53%). For people without PMLD, the most frequently reported things that would be needed to make a future lockdown easier would be support to keep active (76%), support to keep busy (70%) and knowing how long lockdown would last (53%).

4.8.3. Summer holidays

We also asked participants about planned holidays for people with and without PMLD, and these data are presented in Figure 4.37.

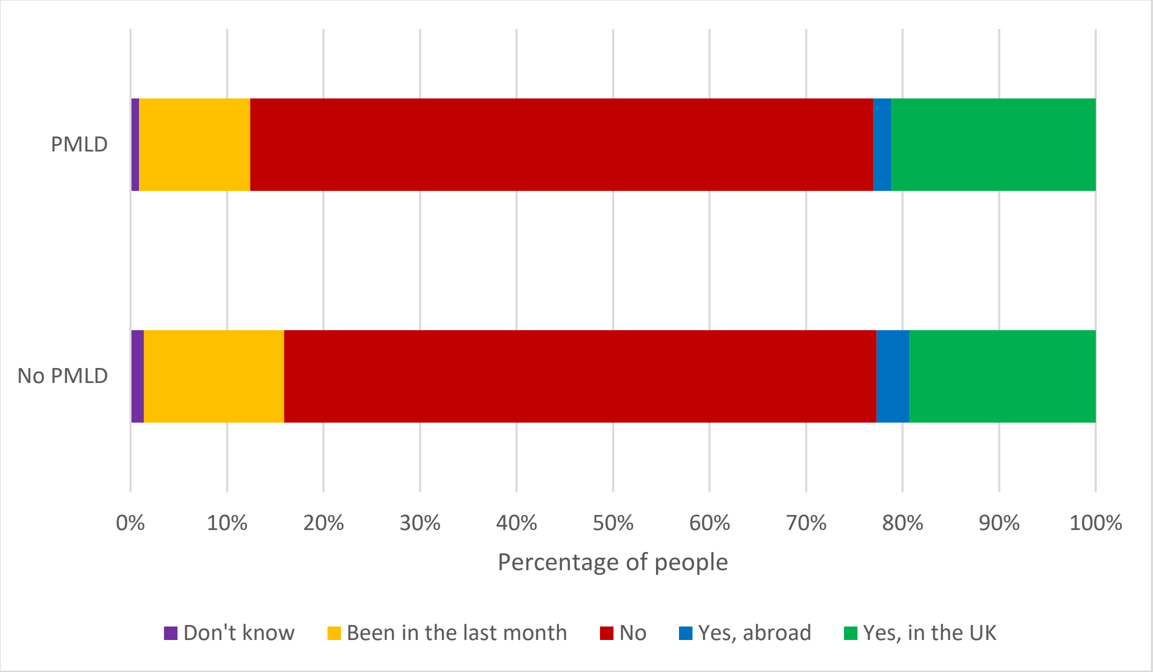

Figure 4.37. Planned holidays for people with learning disabilities

A majority of family carers and paid support workers of people with and without PMLD reported that a holiday for the person was not planned (65% and 61% respectively). A minority had already been on holiday in the month before the survey (12% and 15% respectively), with most planned holidays in the UK (21% and 19% respectively) rather than abroad (2% and 3% respectively).

Version 1.0, September 2021