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Coronavirus and People with Learning Disabilities Study

Wave 4 Results
February 2023

Full Report

Chris Hatton, Sue Caton, Jill Bradshaw, Amanda Gillooly, Andrew Jahoda, Rosie Kelly, Roseann Maguire, Edward Oloidi, Laurence Taggart, Stuart Todd and Richard Hastings

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Waves 1-3.
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Chapter 1: Introduction

1.1. Background and rationale for this study

There are approximately 1.5 million people with learning (intellectual) disabilities across the UK[1]. Throughout the COVID-19 pandemic, data indicated that people with learning disabilities were more likely to contract COVID-19, have a more severe case of COVID-19, and were 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 reported and continue to report 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 earlier reports from the project[5].

Large-scale COVID-19 surveys, with their general population remit, used methods (e.g., online surveys) likely to exclude most people with learning disabilities. Even when these surveys were nationally representative, they did not include sufficient numbers of people with learning disabilities to allow for meaningful analysis across different parts of the UK. They also did not have the flexibility to ask questions of specific relevance to people with learning disabilities. These larger surveys were 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.

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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)

The project reported here uses these direct interview methods and was designed to systematically and responsively track the experiences of adults with learning disabilities through the COVID-19 pandemic over time across the UK, and investigate swiftly actionable factors associated with better outcomes. For Wave 4 of the project, the research team continued to examine the ongoing impact of the pandemic on the lives of people with learning disabilities in the UK. However, by Wave 4 of the project (the focus in this report), the study also began to look more broadly at the current living circumstances of people with learning disabilities in the UK in the context of a pathway into recession and challenges for public services.

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. There have been now four '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 three 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 could and did take part in an interview with a researcher, and Cohort 2 was family carers and support workers 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 fourth 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?

In Wave 4, we contacted the 477 adults with learning disabilities across the UK in Cohort 1 who took part in Wave 3 and gave their consent to be approached about a future wave.

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

In Wave 4, across the UK we contacted the 270 family carers or support workers of people with learning disabilities who could not take part in an interview themselves (Cohort 2) who took part in Wave 3 and gave their consent to be approached about a future wave.

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

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

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

1.2.3. How did we find people?

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

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

1.2.4. How did we collect the data?

Data were collected between 1st September and 2nd December 2022 for Cohort 1, and between 29th September and 7th December 2022 for Cohort 2, with the bulk of data collected in September and October.

1.2.4.1. Cohort 1: Adults with learning disabilities

For the main Wave 4 of the study that is the subject of this report, we directly interviewed 354 adults with mild/moderate learning disabilities across the UK (Cohort

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[7] https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability (accessed 3 January 2023)

1), with an additional participant preferring to complete the schedule themselves using a paper copy of the schedule. Data were entered directly into Qualtrics™ during the interviews. Interviews were undertaken using the preferred digital platform or on the telephone for each participant: Zoom (168 people; 47.3%), telephone (116 people; 32.7%), Microsoft Teams (3 people; 14.9%), WhatsApp (14 people; 3.9%) and FaceTime (3 people; 0.8%). The 355 Cohort 1 participants represent a 66.7% retention rate from the previous round of Wave 3 interviews conducted more than a year previously.

Interviewers contacting potential participants in Cohort 1 noted reasons for non-participation among those who did not take part in Wave 4. These are set out in Table 1.1 below.

Table 1.1 Reasons for non-participation

	Number of participants
Did not respond to attempts to contact	57
Stated that no longer wished to take part (reasons included: too busy, bereavements, poor mental health)	55
Contact details now inaccurate	13
Initially said would participate but failed attempts to set up interview	21
Died	2

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

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

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

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

In Cohort 2 at Wave 4, participants were the family carers and support workers of 192 adults with learning disabilities. This also represents a 66.7% retention rate from the previous round of Wave 3 surveys conducted more than a year previously.

1.2.5. How did we analyse the data?

1.2.5.1. Quantitative data

The analysis for Wave 4 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. For selected indicators where information was also collected in previous waves, descriptive comparisons using whole cohorts at each time point have been made.

It was also the case that some survey items related to specific sub-groups of people. If so, we report the number who completed the question alongside the summary data. 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 4 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] was published in the *Tizard Learning Disability Review*.

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[8] https://www.emerald.com/insight/content/doi/10.1108/TLDR-09-2021-0027/full/html

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

2.1. Who took part?

At Wave 4, in Cohort 1 data were available for this report for 355 people with learning disabilities and, in Cohort 2 for 192 family carers or support workers of people with learning disabilities. The total number of participants who were recruited in each country is shown in Figure 2.1 below, separated by cohort.

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

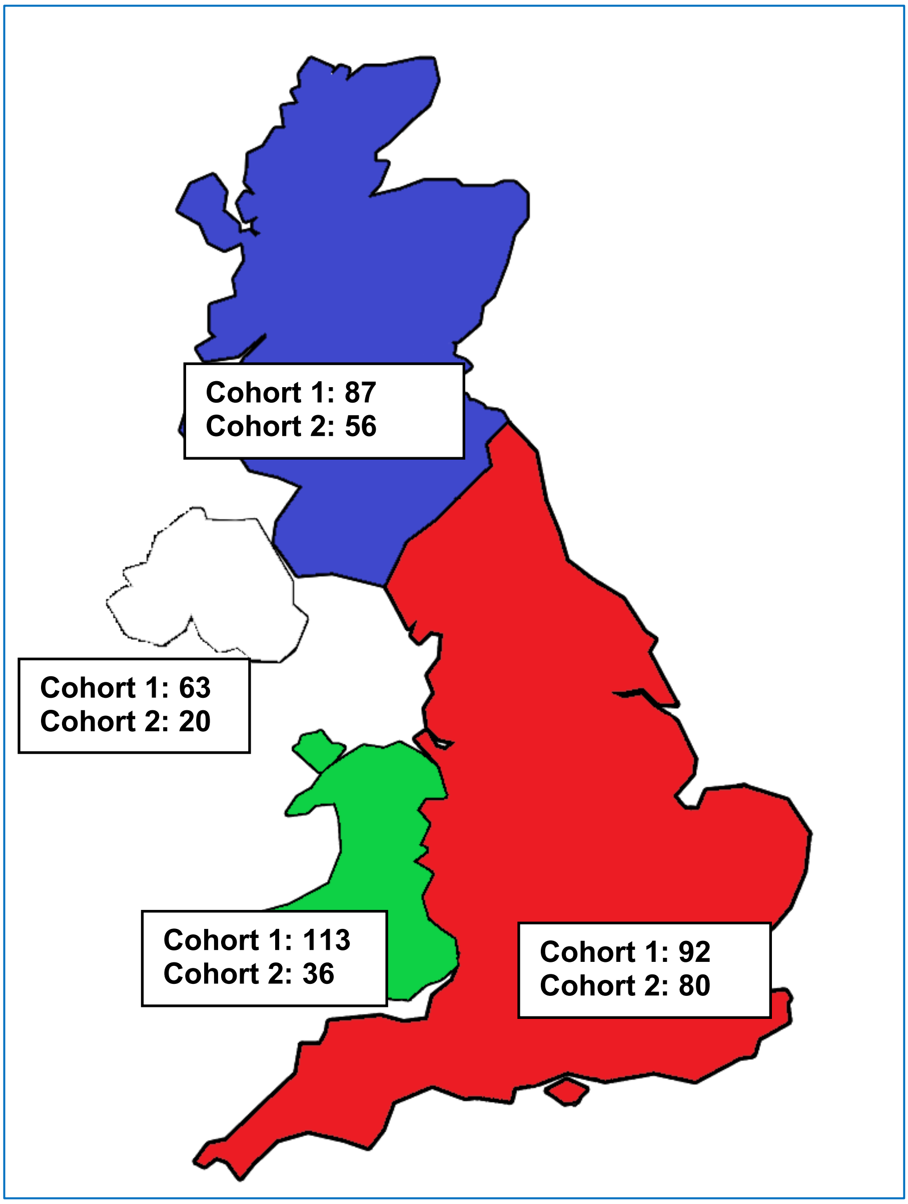

Figure 2.1. A map of the UK showing number of people who took part in the study in each country at Wave 4, by cohort

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

	Cohort 1 (N = 355)	Cohort 2 (N = 192)
Gender		
Male	51%	56%
Female	48%	44%
Other	1%	0%
Age		
16-24	9%	26%
25-34	32%	38%
35-44	28%	21%
45-54	16%	8%
55-64	11%	5%
65+	4%	3%
Ethnicity		
Asian	1%	2%
Black	3%	0%
Mixed ethnic backgrounds	2%	3%
White British	90%	90%
White – Irish, Roma, Gypsy or Irish Traveller, Other	4%	5%
Relationship to person cared for		
Family Carer		93%
Paid Support Worker		6%
Other e.g. friend		1%
Does "PMLD" apply to the person with learning disabilities		
Yes		45%
No		47%
Don't know		8%
Down syndrome	12%	22%
Professional label of autism or Asperger's syndrome		
Yes	22%	48%
No, but self-identifies or carer/supporter identifies person as autistic	1%	11%

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

The number of men and women was broadly similar in Cohort 1, with a majority of men in Cohort 2. People with learning disabilities from Cohort 2 were generally younger than people with learning disabilities in Cohort 1, but there was a range of ages in both cohorts. Most people with learning disabilities were White British, with few people from ethnic minorities in either cohort at Wave 4.

At Wave 4, 12% of people in Cohort 1 and 22% of people in Cohort 2 had a label of Down syndrome. Within Cohort 2 at Wave 4, almost half (45%) of family carers or support workers said that the term “PMLD” applied to the person they were caring for/supporting. In Cohort 1, 22% of people said that a professional had given them a label of autism or Asperger’s syndrome, with a very small number of further people identifying themselves as autistic in the absence of a professional diagnosis. In Cohort 2 the figures were much higher – almost half of people (48%) had a professional label of autism and a further 11% of family carers or support workers thought that the person they cared for/supported was autistic in the absence of a professional diagnosis.

The majority of people with learning disabilities in Cohort 1 lived alone (31%) or with their family (41%), either with or without support workers coming into their home (see Table 2.2). In Cohort 2, the majority of people with learning disabilities lived with their family (60%) with or without support workers coming into their home. In Cohort 1, 29 people with learning disabilities reported that they look after someone who they lived with, most commonly a parent (8 people), children (8 people), a partner (7 people), or other family members (3 people).

Table 2.2. Who people with learning disabilities live with (Wave 4 participants)

	Cohort 1	**Cohort 2**
Who does the person with learning disabilities live with?		
Live alone with no support from staff	8%	1%
Live alone with support in supported living, privately rented, or privately owned accommodation	23%	9%
Live with their partner with no support from staff	3%	
Live with their partner with support workers coming into their home	3%	
Live with family with no support from staff	37%	40%
Live with family with support workers coming into their home	4%	20%
Live in supported/independent living, but have moved back to family home because of COVID-19	0%	
Live in a Shared Lives arrangement	1%	3%
Live with other people with learning disabilities with no support from staff	0%	
Live with other people with learning disabilities with support workers coming into their home during the day	4%	
Live with other people with learning disabilities with support workers coming into their home during the day and night	17%	
Live with other people with support in supported living accommodation		13%
Live with other people with support in residential care		11%
Live with other people with learning disabilities with support, with home ownership		1%
Live in a secure placement		1%
Live in a different type of home		2%
The person with learning disabilities looks after someone they live with (N = 244)	12%	

2.2. COVID-19

In this sub-section, we report findings from questions in the interviews and surveys relating specifically to COVID-19, including questions about having COVID-19, vaccinations, testing, keeping safe, and sources of information about COVID-19.

2.2.1. Having COVID-19

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 2.2 and 2.3.

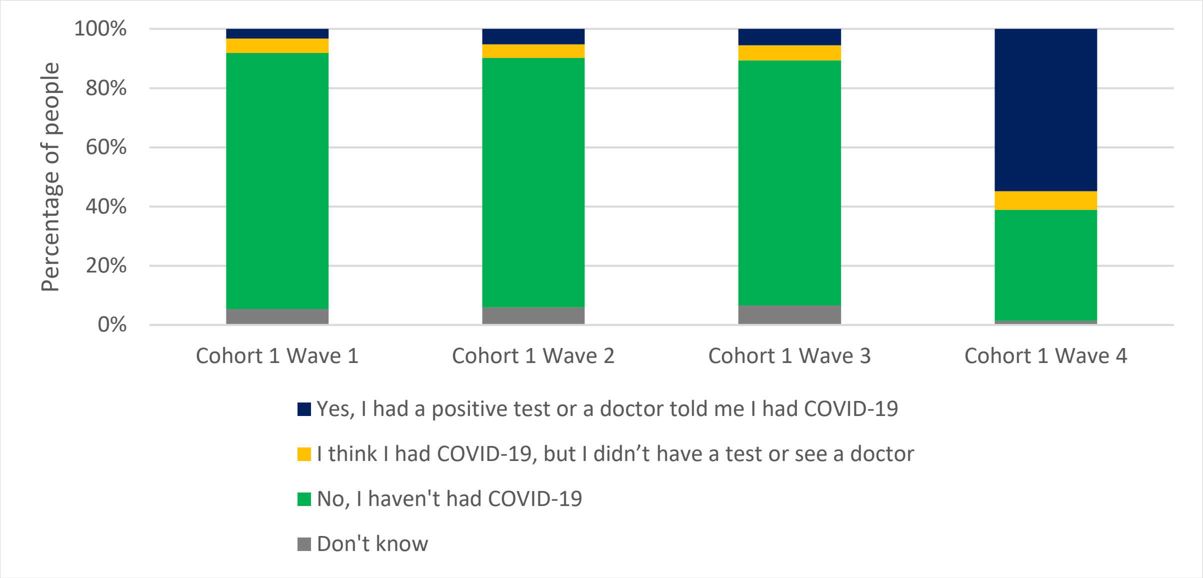

Figure 2.2. Do you think you have ever had COVID-19? (Cohort 1)

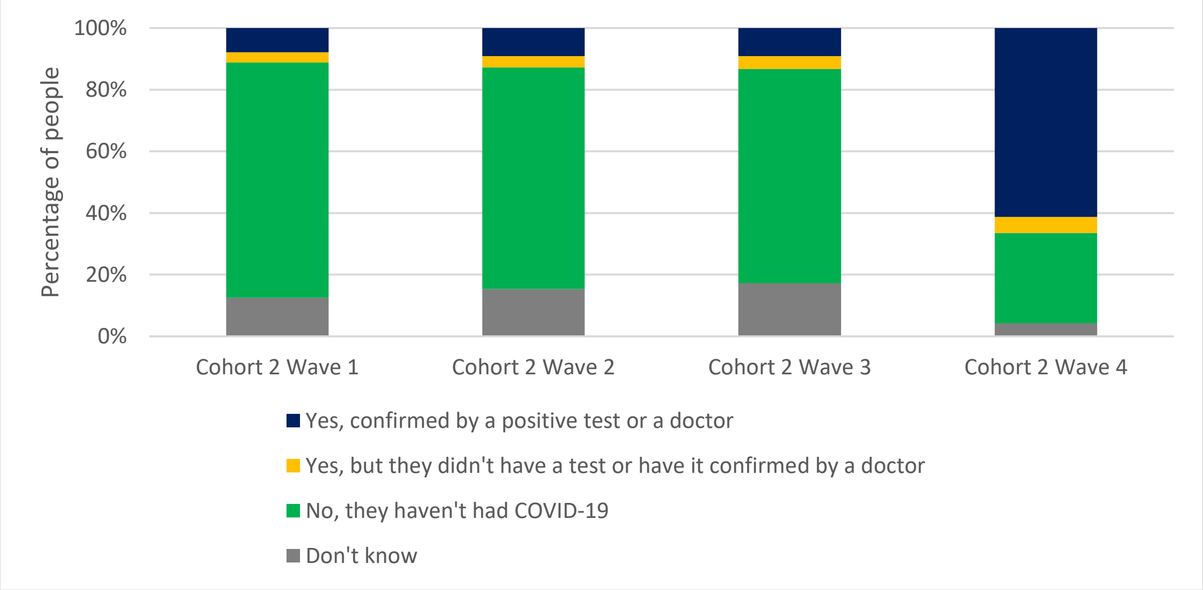

Figure 2.3. Do you think the person you support/care for ever had COVID-19? (Cohort 2)

For Cohort 1, the prevalence of suspected or confirmed COVID-19 increased slowly from 8% at Wave 1 (Dec 2020-Feb 2021) through to 11% at Wave 3 (July-Aug 2021), but increased substantially to 61% by Wave 4 (Sept-Dec 2022). The pattern was similar for Cohort 2, with the prevalence of COVID-19 increasing from 11% at Wave 1 to 13% at Wave 3, then increasing to 67% at Wave 4.

The majority of people who had had COVID-19 at Wave 4 were reported to have had the virus once (84% Cohort 1; 83% Cohort 2). During their most recent episode of COVID-19, eight people in Cohort 1 (4% of those who had had COVID-19) reported they had been hospitalised, and 10 (5%) reported that they had been treated with antivirals. In Cohort 2, 2 people (2% of those who had had COVID-19) had been hospitalised and 8 people (6%) had been treated with antivirals.

By Wave 4, in Cohort 1 four people (2% of those who had had COVID-19) reported being told by a doctor they had long COVID/post-COVID syndrome, with one person reporting still having long COVID/post-COVID syndrome at the time of the interview. Among Cohort 2, three people (2%) were reported to have had long COVID/post-COVID syndrome, with two people (2%) still having long COVID/post-COVID syndrome at the time of the survey.

2.2.2. COVID-19 vaccinations

We asked participants in both cohorts about whether the person with learning disabilities had received a COVID-19 vaccination, and if so how many doses they had received. These data are displayed in Figure 2.4.

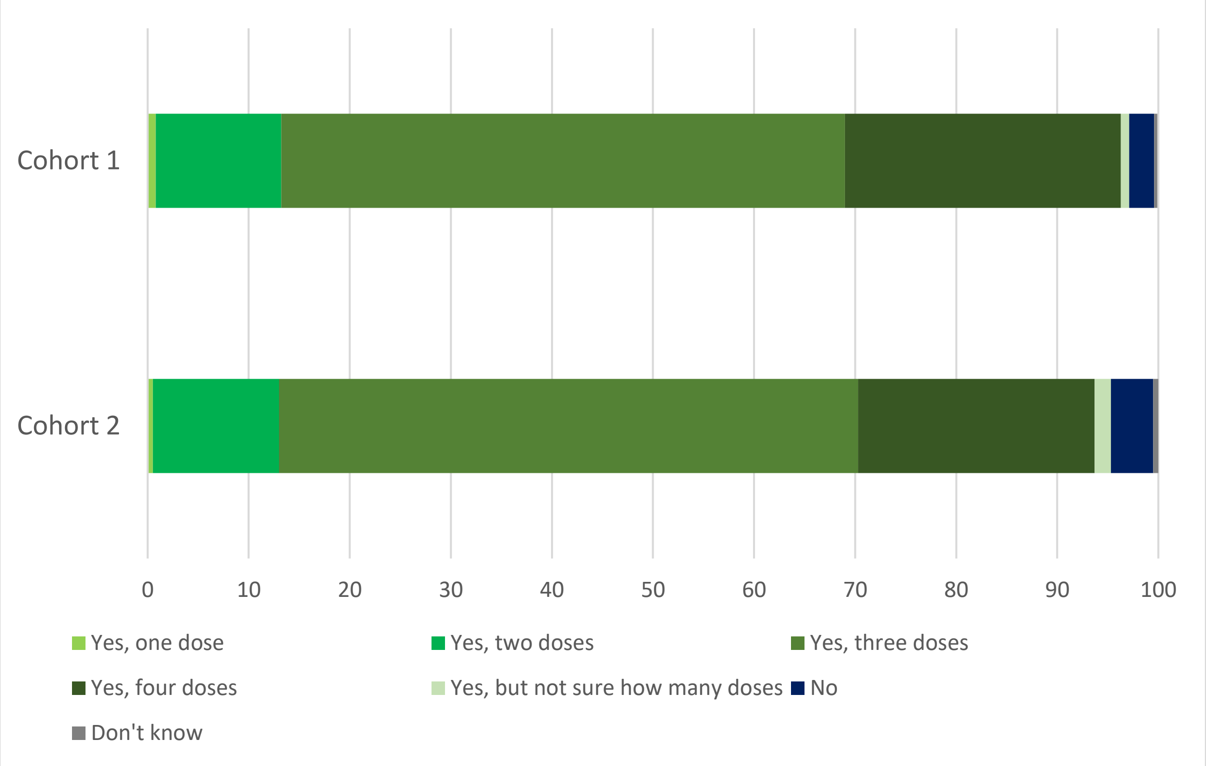

Figure 2.4. COVID-19 vaccination receipt in people with learning disabilities at Wave 4

The vast majority of participants in both cohorts (>95%) reported that they (Cohort 1), or the person they supported/cared for (Cohort 2), had received at least one dose of the COVID-19 vaccination, with the majority of people in both cohorts having had three or four doses of the vaccine by Wave 4 (83% Cohort 1; 81% Cohort 2).

When asked about whether they (Cohort 1) or the person they support/care for (Cohort 2) would take a booster COVID-19 vaccination in winter 2022 if this were needed, a substantial majority of participants in both cohorts (>85%) indicated that they, or the person they supported/cared for, would be willing to have this.

When people responded that they would not be willing to have a booster vaccination, they were asked an open-ended question to indicate why they were not willing.

Selected quotes from both cohorts are shown below in Box 1.1 for Cohort 1 and Box 1.2 for Cohort 2.

Box 1.1. Reasons for not wanting to have a booster vaccination (Cohort 1 only)

"I think two is enough. I'm not really at risk"

“It feels enough now”

"After hearing about all the conspiracy theories and people being ill after the jab and having long term effects"

"It gave me a sore arm"

"Because of my previous reaction to vaccines"

“Don’t think it would help in anyway”

"Because I felt unwell after the last one"

Box 1.2. Reasons for not wanting to have a booster vaccination (Cohort 2 only)

“He had a severe reaction to last booster suffering a seizure”

“The person is very healthy; has already had Covid (despite 3 vaccinations); and suffered side-effects from vaccination”

“They refuse to have injections, point blank”

“Hyper-sensitive plus clash with anti-epilepsy drugs”

2.2.3. Testing for 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.

In Wave 4, a substantial minority of people in Cohort 1 (40%) had had a COVID-19 test in the last four weeks, a similar level to that reported in Wave 3 (37%). The figures for Cohort 2 are similar (44% at Wave 4; 37% at Wave 3). This indicates that the prevalence of people getting COVID-19 testing may not have decreased and may have increased in the year or more from Wave 3 to Wave 4.

Where tests had been done, we asked about the frequency of these tests. These data are displayed in Figure 2.5 below for Wave 3 and Wave 4.

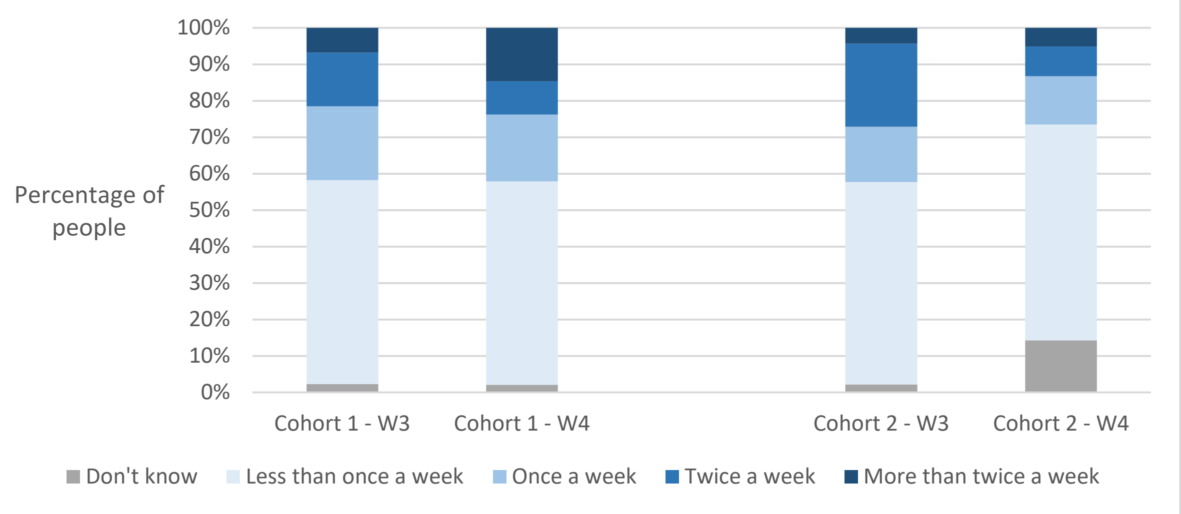

Figure 2.5. In the last four weeks, how many times have you/they had a test? (Sample Wave 4: Cohort 1 = 146; Cohort 2 = 97)

At Wave 4 the most commonly reported frequency of tests in Cohort 1 and Cohort 2 was less than once a week (56% and 60% respectively), with some signs that the overall frequency of COVID-19 tests had slightly decreased from Wave 3 to Wave 4. Relatively few people reported paying for COVID-19 tests (6% Cohort 1; 9% Cohort 2) by the time of the Wave 4 interview/survey.

Among those who had a COVID-19 test in the last four weeks, their reasons for having a COVID-19 test at Wave 4 are included in Figure 2.6 below. People in Cohort 1 most commonly had a COVID-19 test because they had potential COVID-19 symptoms (32%), because they took tests regularly (29%), or for a range of other reasons (22%). For people in Cohort 2 reasons for taking a test in the last four weeks were more evenly distributed, between the person having potential COVID-19 symptoms (24%), the person being in contact with someone who might have COVID-19 (23%), regularly taking tests (22%), and a range of other reasons (26%).

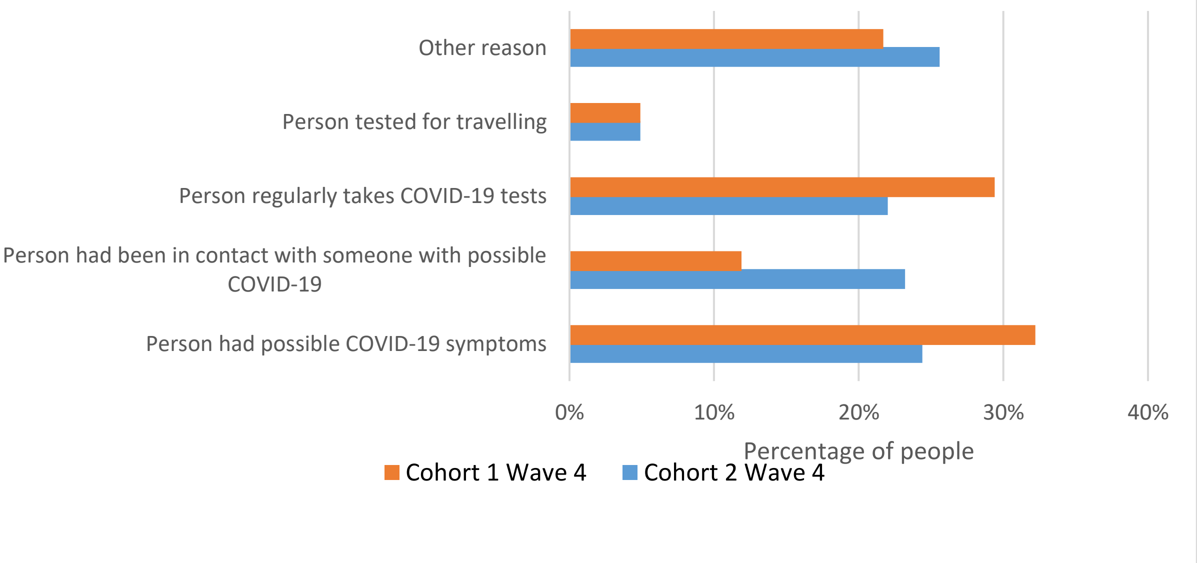

Figure 2.6. Reasons for doing COVID-19 tests – Wave 4

2.2.4. Keeping safe from COVID-19

We asked both cohorts about whether they (Cohort 1) or the person they support/care for (Cohort 2) were doing anything at the moment to keep safe from COVID-19 – people could select as many options as applied to them. These data are presented in Figure 2.7 for Cohort 1 and Cohort 2 at Wave 4.

Over a quarter of people in Cohort 1 (26%) said they weren't doing anything to keep themselves safe from COVID-19. The most common responses for people in Cohort 1 were washing their hands more than before the COVID-19 pandemic (54% of people), wearing a face mask sometimes when out (33%) and trying not to be in big groups of people (23%). Over a third of people in Cohort 2 (35%) were reported not to be doing anything to keep themselves safe from COVID-19. People in Cohort 2 were less likely than people in Cohort 1 to be washing their hands more often (39% Cohort 2; 54% Cohort 1) or wearing a face mask sometimes when out (24% Cohort 2; 33% Cohort 1). However, people in Cohort 2 were more likely than people in Cohort 1 to be restricting their lives in various ways to keep themselves safe from COVID-19, such as trying not to be in big groups of people (36% Cohort 2; 23% Cohort 1), staying at home more (25% Cohort 2; 6% Cohort 1), and trying not to use public transport (17% Cohort 2; 6% Cohort 1).

By Wave 4, one person in Cohort 1 (0.3%) was shielding, compared to 3% of people in Cohort 1 at Wave 3. In Cohort 2, by Wave 4 four people (2.1%) were shielding, compared to 19% of people in Cohort 2 at Wave 3.

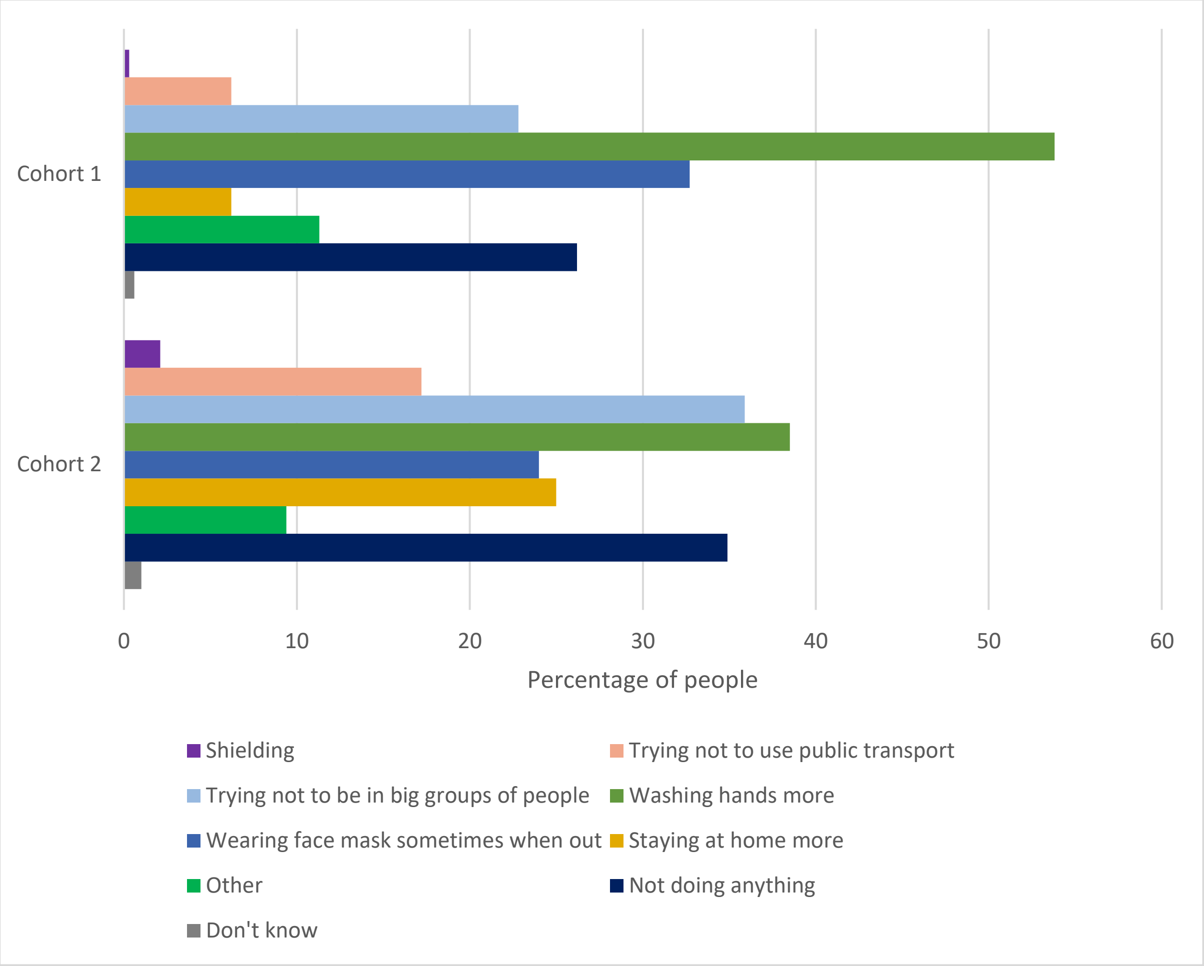

Figure 2.7. Wave 4 – what people are doing at the moment to keep themselves safe from COVID-19 (tick all that apply)

It is also worth noting that at Wave 4 over a quarter (28%) of family members or support workers of people in Cohort 2 reported that they were still wearing PPE (e.g. masks, gloves or aprons) when in close contact with the person they were supporting/caring for, similar to the 29% reported at Wave 3.

2.2.5. Information about COVID-19

We asked participants about how they had found out anything they wanted to know about COVID-19 in the four weeks before the interview (people with learning disabilities) or survey (family carers or support workers). These data are presented in Figure 2.8.

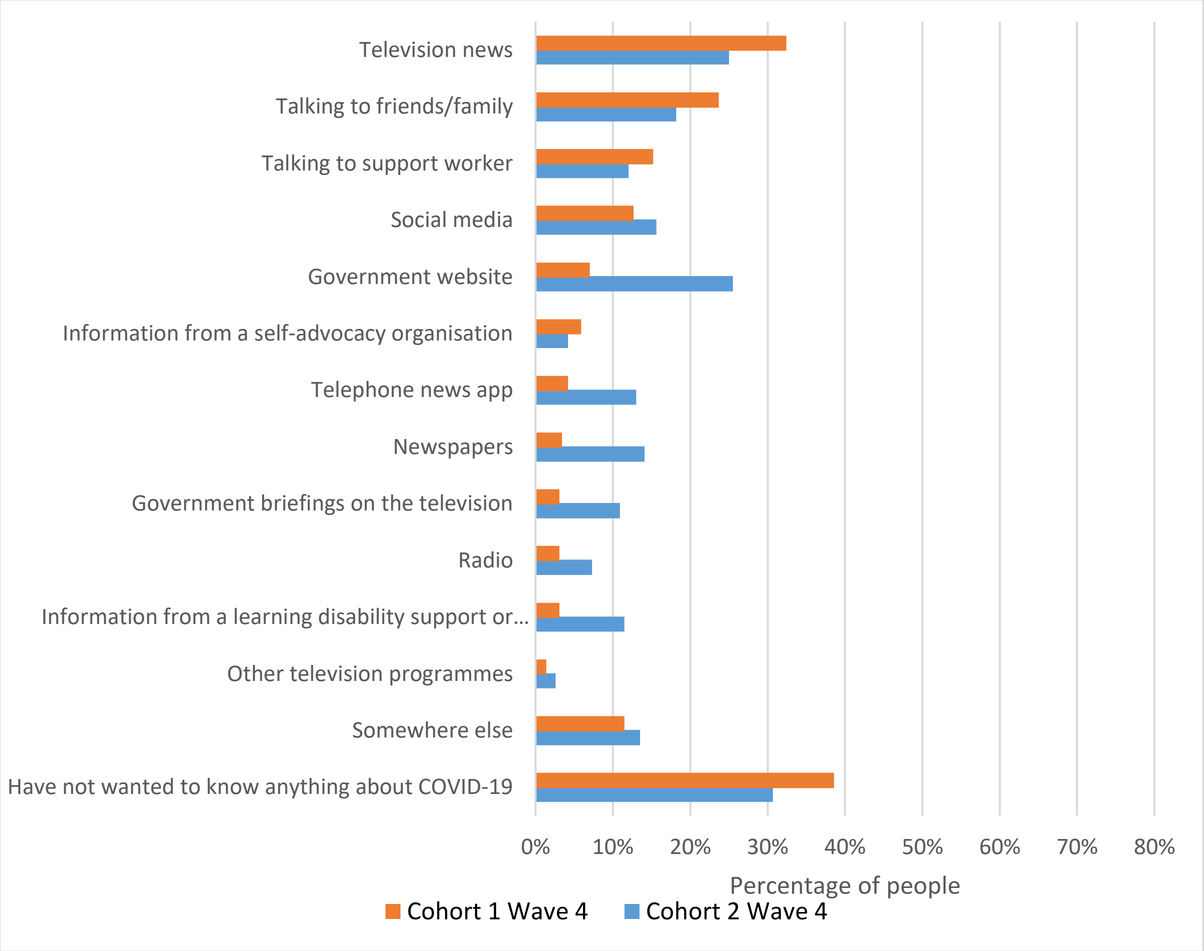

Figure 2.8. In the last four weeks, how have you (Cohort 1) or how have you as the person's family carer or support worker (Cohort 2) found out anything you've wanted to know about COVID-19? (Select all that apply)

By Wave 4, over a third of people with learning disabilities in Cohort 1 (39%) and just under a third of family carers and support workers in Cohort 2 (31%) said they had not wanted to know anything about COVID-19 in the last four weeks. For Cohort 1, four sources of information were used by more than 10% of people, most commonly television news (32% of people) and talking to friends/family (24%). For Cohort 2, nine sources of information were used by more than 10% of family carers/support workers, most commonly government websites (26%) and television news (25%).

Although the wording of questions about information sources was not exactly the same in Wave 3, it is clear that the number of people in both Cohort 1 and Cohort 2 seeking information about COVID-19 decreased substantially from Wave 3 to Wave 4. For example, the proportion of people in Cohort 1 getting information about COVID-19 from TV news decreased from 69% of people to 24% of people at Wave 4; for family carers and support workers of people in Cohort 2 the decrease was from 44% at Wave 3 to 25% at Wave 4.

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 current health (Cohort 1) or the health of the person with learning disabilities who they support/care for (Cohort 2), with Figures 2.8 and 2.9 showing the findings for cohorts across all four waves.

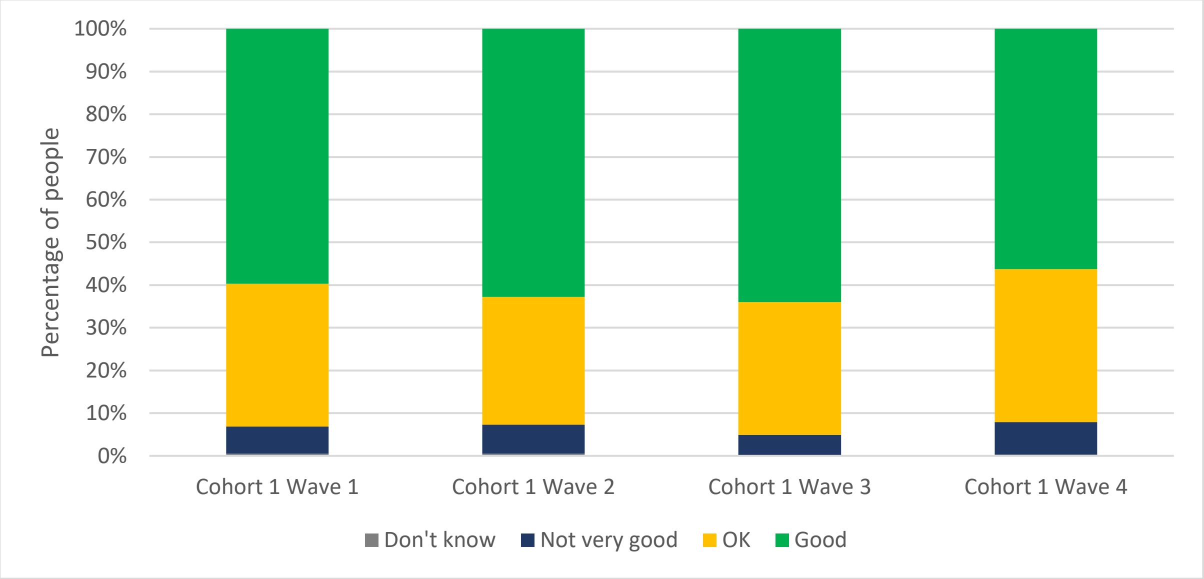

Figure 2.8: How is your health today? (Cohort 1)

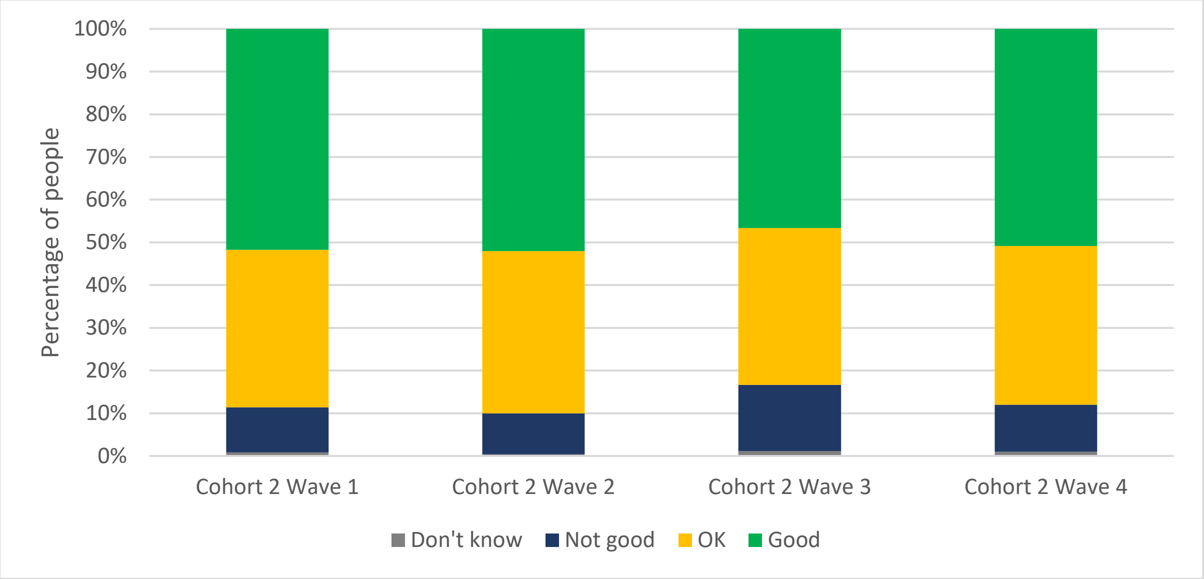

Figure 2.9: How is the health of the person you care for/support today? (Cohort 2)

Across all four waves, a majority of people in Cohort 1 reported their health as good. Self-reported health was slightly more positive for the cohorts of people in Cohort 1 at Wave 2 and Wave 3, but by Wave 4 was the least positive across all four waves.

The health of around half of people in Cohort 2 was reported as good by family carers or support workers across all four waves, with the health of around 10% of people reported as not good. Among Cohort 2, people's health was reported to be least positive at Wave 3; reported health at Wave 4 was similar to that reported at Wave 1 (early 2021, at a time of reinstated national lockdowns).

At Wave 4, almost a quarter of people in Cohort 1 (24%) reported that in the last four weeks their existing health problems had worsened or they had had new (non-COVID-19) health conditions, compared to 19% of people who reported this at Wave 3. For people in Cohort 2 at Wave 4, just over a quarter of people (26%) were reported to have new or worsening health conditions in the last four weeks, compared to 28% of people at Wave 3.

2.3.2. Contact with GPs

In Waves 2, 3 and 4 we asked people with learning disabilities (Cohort 1) or family carers/support workers (Cohort 2) whether the person with learning disabilities had been in contact with a GP in the last four weeks, and whether they had seen the GP in person (rather than by 'phone or video link). In Wave 1 we asked this question differently, in relation to GP contact before the pandemic started and since the start of the COVID-19 pandemic.

Figure 2.10 below shows the percentage of people in Cohort 1 and Cohort 2 who had not seen their GP in the last four weeks, and the percentage of people who had seen their GP in person, across Waves 2, 3 and 4. For Cohort 1, around two thirds of people (67%) at Wave 4 had not seen their GP in the last four weeks, similar to

Wave 2 (April/May 2021) and Wave 3 (July/August 2021). Just under a quarter (23%) of people in Cohort 1 saw their GP in person at Wave 4, an increase from 14% of people at Wave 2. At Wave 1, 43% of people in Cohort 1 had reported that they used to see their GP regularly before the first COVID-19 lockdown.

For Cohort 2, less than two-thirds of people (63%) were reported not to have seen their GP in the last four weeks at Wave 4, an increase from Wave 2 (58%) but a slight decrease from Wave 3 (65%). Around one in seven (15%) of people in Cohort 2 had seen their GP in person at Wave 4, an increase from 7% of people at Wave 2. At Wave 1, 40% of people in Cohort 2 were reported to have seen their GP regularly before the first COVID-19 lockdown.

For both Cohort 1 and Cohort 2, GP appointments not in person were mostly by ‘phone rather than video link.

At Wave 4, we also asked how people would prefer to talk to their GP. The vast majority of people in Cohort 1 (88%) wanted to see their GP face to face, with relatively small numbers wanting to talk to their GP by ‘phone (5%) or video link (2%). A small minority of people in Cohort 1 (6%) said that their preference would depend on the issue. For Cohort 2, just over half of family carers or support workers (52%) wanted to see the GP face to face, with 16% wanting to talk to the GP by ‘phone and 6% wanting to talk via video link. A quarter of family carers or support workers in Cohort 2 (25%) said that their preference would depend on the issue.

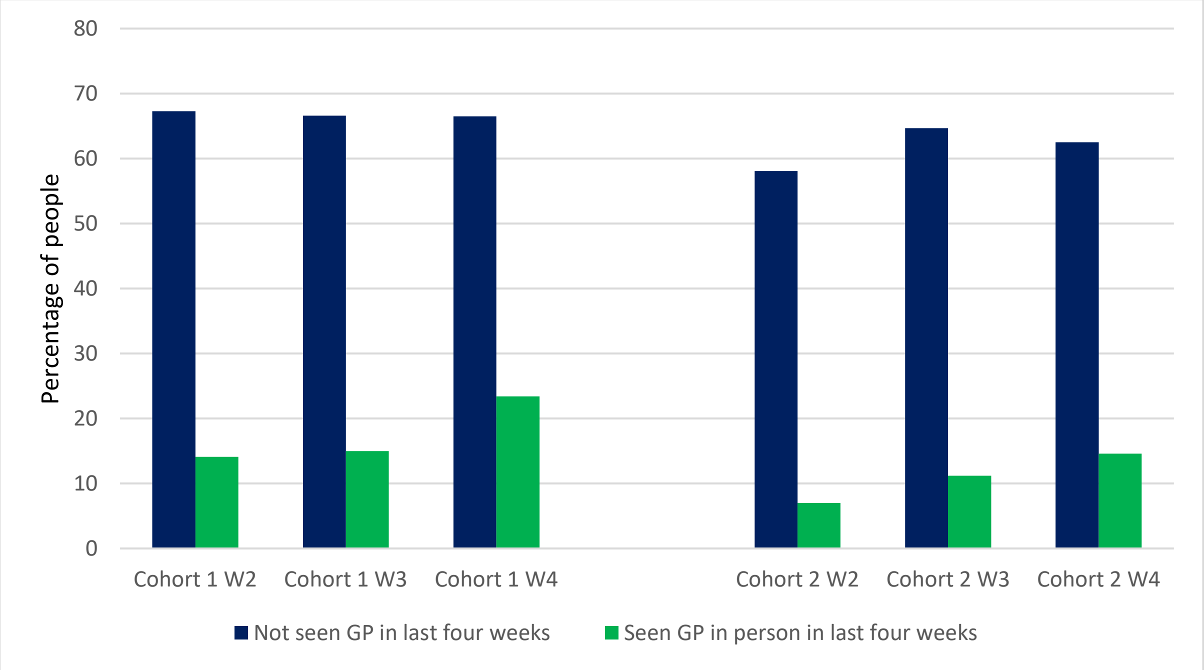

Figure 2.10. In the last four weeks have you/the person you support/care for been in contact with a GP? Wave 2, Wave 3, Wave 4

In Wave 4, we asked some additional questions about people’s experiences of GP services. Around a quarter of people in Cohort 1 (26%) and Cohort 2 (22%) saw the same GP every time, rather than having appointments with different GPs.

Less than half of people in Cohort 1 (42%) and Cohort 2 (47%) at Wave 4 reported that it was easy to get in contact with the GP when they needed to. For people in Cohort 1, the most common problems with contacting their GP were not being able to get through on the ‘phone (21% of all people in Cohort 1), no GP appointments being available (17%) and ‘phone booking being too complicated (9%). For family carers or support workers in Cohort 2, the most common problems with contacting the GP were not being able to get through on the ‘phone (27%), no GP appointments being available (25%), not being able to get to the GP surgery to make an appointment (10%) and ‘phone (7%) and online (5%) booking systems being too complicated.

2.3.3. Contact with other health professionals

Using the same format of questions we asked concerning contact with GPs in the last four weeks, at Waves 2, 3 and 4 we asked about contact with: community nurses; psychiatrists/clinical psychologists/counsellors; and other therapists (e.g. speech and language therapists; occupational therapists or physiotherapists).

Figure 2.11 presents the findings for contact with a community nurse. For Cohort 1, at Wave 4 the vast majority of people (88%) had not seen a community nurse in the last four weeks, compared to 84% of people not seeing a community nurse at Wave 2. At Wave 4, 10% of all people in Cohort 1 had seen a community nurse in person in the last four weeks, a consistent percentage across Waves 2, 3 and 4. At Wave 1, 22% of people in Cohort 1 had reported they saw a community nurse regularly before the first COVID-19 lockdown.

For Cohort 2, at Wave 4 a substantial majority of people (81%) were reported not to have seen a community nurse in the last four weeks, compared to 69% of people not seeing a community nurse at Wave 2. At Wave 4, 13% of all people in Cohort 2 had seen a community nurse in person in the last four weeks, a fairly consistent percentage across Waves 2, 3 and 4. At Wave 1, 27% of people in Cohort 2 were reported to have regularly seen a community nurse before the first COVID-19 lockdown.

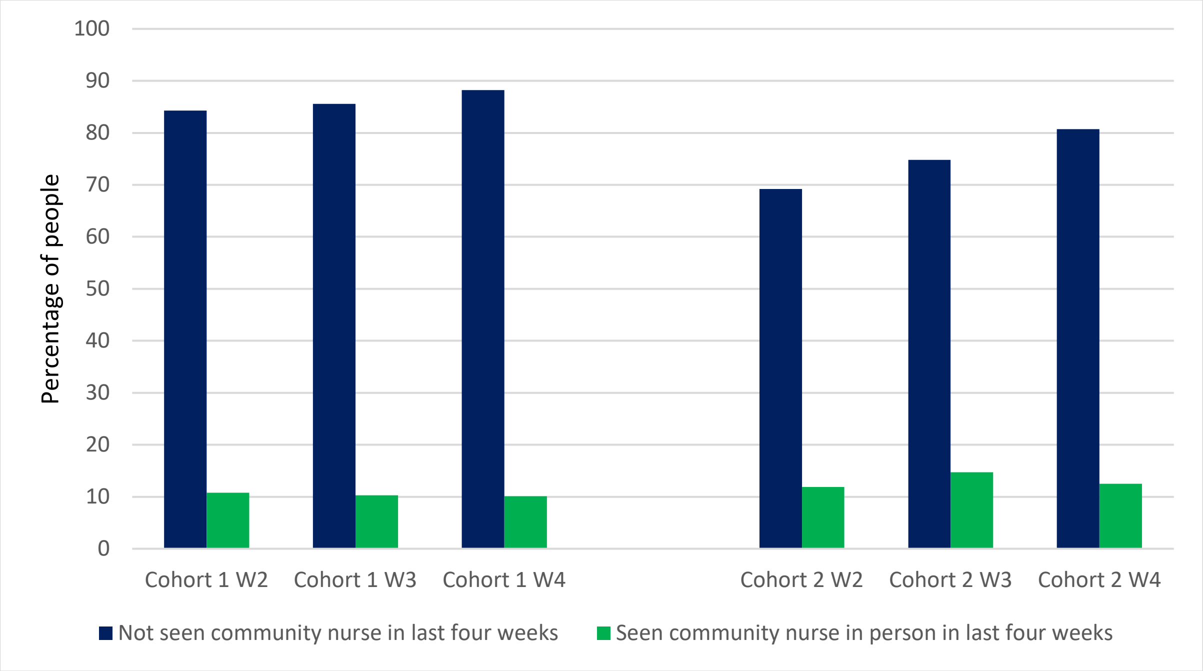

Figure 2.11. In the last four weeks have you/the person you support/care for been in contact with a community nurse? Wave 2, Wave 3, Wave 4

Figure 2.12 presents the findings for contact with a psychiatrist, clinical psychologist or counsellor. For Cohort 1, at Wave 4 the vast majority of people (89%) had not seen a mental health professional in the last four weeks, a consistent level across Waves 2, 3 and 4. At Wave 4, 10% of all people in Cohort 1 had seen a mental health professional in person in the last four weeks, increasing from 2% at Wave 2. At Wave 1, 20% of people in Cohort 1 had reported seeing a mental health professional regularly before the first COVID-19 lockdown. At Wave 4 we asked people which mental health professional(s) they had seen, with 16 people reporting seeing a psychiatrist, 14 people seeing a clinical psychologist, and 10 people seeing a counsellor.

For Cohort 2, at Wave 4 the vast majority of people (87%) were reported not to have seen a mental health professional in the last four weeks, compared to 77% of people not seeing a mental health professional at Wave 2. At Wave 4, 7% of all people in Cohort 2 had seen a mental health professional in person in the last four weeks, a slight increase from 5% at Wave 2. At Wave 1, 23% of people in Cohort 2 were reported to have regularly seen a mental health professional before the first COVID-19 lockdown. At Wave 4, 18 people with learning disabilities in Cohort 2 were reported to have seen a psychiatrist, 7 people to have seen a clinical psychologist, and 1 person to have seen a counsellor.

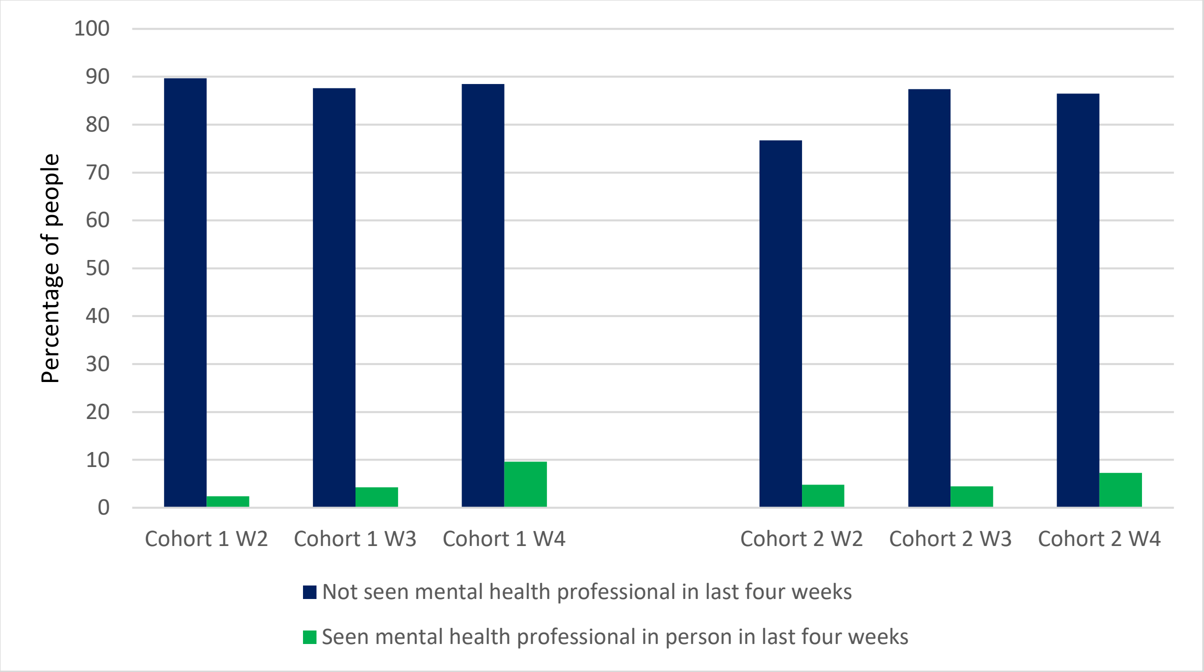

Figure 2.12. In the last four weeks have you/the person you support/care for been in contact with a psychiatrist, clinical psychologist or counsellor? Wave 2, Wave 3, Wave 4

Figure 2.13 presents the findings for contact with another type of therapist, such as a speech and language therapist, occupational therapist or physiotherapist. For Cohort 1, at Wave 4 the vast majority of people (92%) had not seen another type of therapist in the last four weeks, a consistent level across Waves 2, 3 and 4. At Wave 4, 8% of all people in Cohort 1 had seen another type of therapist in person in the last four weeks, increasing from 4% at Wave 2. At Wave 1, 15% of people in Cohort 1 had reported that they saw another type of therapist regularly before the first COVID-19 lockdown. At Wave 4 we asked people which types of therapist(s) they had seen, with 18 people reporting seeing a physiotherapist, 4 people seeing a speech and language therapist, and 6 people seeing an occupational therapist.

For Cohort 2, at Wave 4 just under three quarters of people (73%) were reported not to have seen another type of therapist in the last four weeks, a fairly consistent level across Waves 2, 3 and 4. At Wave 4, 21% of all people in Cohort 2 had seen another type of therapist in person in the last four weeks, an increase from 14% at Wave 2. At Wave 1, 32% of people in Wave 2 were reported to have regularly seen another type of therapist before the first COVID-19 lockdown. At Wave 4, 18 people with learning disabilities in Cohort 2 were reported to have seen a physiotherapist, 13 people to have seen a speech and language therapist, and 20 people to have seen an occupational therapist.

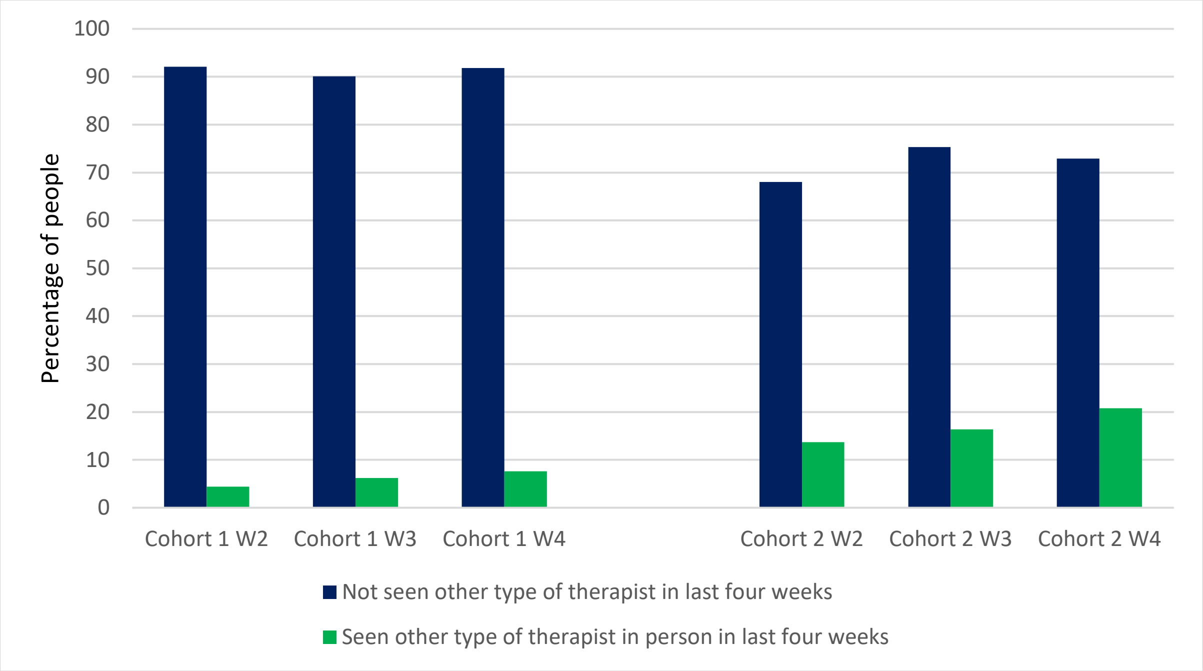

Figure 2.13. In the last four weeks have you/the person you support/care for been in contact with another type of therapist? Wave 2, Wave 3, Wave 4

2.3.4. Dentists, eye tests and hearing tests

For the first time in Wave 4, we asked questions about contact with dentists, eye tests, and hearing tests.

Over half of people in Cohort 1 (57%) reported going to the dentist in the last year, with 18% of people reporting toothache in the last 6 months. Over two thirds of people in Cohort 2 (70%) were reported to have gone to the dentist in the last year, with 8% of people reported to have had toothache in the last 6 months.

Just under half (49%) of people in Cohort 1 reported having their eyes tested in the last year, with 21% reporting an eye test 1-2 years ago and 14% reporting an eye test more than 2 years ago. In Cohort 1, 5% of people reported never having had an eye test, and 11% of people did not know or could not remember when they last had an eye test. In Cohort 2, just over a third (37%) of people in Cohort 2 were reported to have had their eyes tested in the last year, with a further 20% having their eyes tested 1-2 years ago, and 33% having their eyes tested more than 2 years ago. In Cohort 2, 6% of people with learning disabilities were reported to never have had their eyes tested and 4% of family carers or support workers did not know or remember if the person with learning disabilities had had their eyes tested.

Relatively few people (12%) in Cohort 1 reported having their hearing tested in the last year, with a further 6% reporting a hearing test 1-2 years ago and 19% reporting a hearing test more than 2 years ago. In Cohort 1, over a third of people (38%) reported never having had a hearing test, and almost a quarter (24%) did not know or could not remember when they last had a hearing test. Few people with learning disabilities in Cohort 2 (8%) were reported to have had their hearing tested in the last year, with a further 5% reported to have had a hearing test 1-2 years ago and 42% reported to have had a hearing test more than 2 years ago. Almost a third of people with learning disabilities in Cohort 2 (29%) were reported to have never had a hearing test, with 15% of family carers or support workers not knowing or not being able to remember when the person with learning disabilities had last had a hearing test.

2.3.5. Planned medical tests, appointments, and operations

We also asked about what had happened to planned medical tests, operations, and outpatient hospital appointments in the last four weeks. These data are presented in Table 2.3 for both cohorts at Wave 4.

Table 2.3. 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	4%	7%
	No	96%	90%
	Don't know		3%
Planned medical operation cancelled			
	Yes	1%	1%
	No	99%	99%
	Don't know		0%
Planned hospital appointment cancelled			
	Yes	4%	9%
	No	96%	91%
	Don't know		1%

A higher percentage of people with learning disabilities in Cohort 2 were reported to have had a medical test (7%), operation (1%), or hospital appointment (4%) cancelled in the last week than in Cohort 1 (4%, 1%, and 3% respectively). These percentages for Wave 4 are similar to those reported for Wave 2 and Wave 3.

We asked follow-up questions about whether people with learning disabilities were currently waiting for planned medical tests, operations and hospital appointments, as shown in Table 2.4 for Wave 4.

Table 2.4. People with learning disabilities waiting for a planned medical test, operation, or hospital appointment – Wave 4

		Cohort 1	Cohort 2
Are they waiting for a planned medical test?			
	Yes	13%	22%
	No	87%	76%
	Don't know		2%
Are they waiting for a planned medical operation?			
	Yes	6%	6%
	No	94%	94%
	Don't know		<1%
Are they waiting for a planned hospital appointment?			
	Yes	17%	32%
	No	83%	68%
	Don't know		<1%

At Wave 4, more people with learning disabilities in Cohort 2 were waiting for a planned medical test (22%), operation (6%), or a hospital appointment (32%) than in Cohort 1 (13%, 6%, and 17% respectively). A large proportion of people with learning disabilities in Cohort 1 (>30%) and Cohort 2 (>49%) had been waiting for more than 6 months for their medical test, operation, or hospital appointment. Similar percentages of people in both cohorts at Wave 3 were waiting, and waiting more than 6 months, for medical tests, operations and hospital appointments.

2.3.6. 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), although the timing of their widespread introduction has varied across the UK. Further information about annual health checks is presented in Figure 2.14 for Cohort 1 and Cohort 2 across Wave 3 and Wave 4.

The question asked whether people had had an annual health check since the beginning of the calendar year – 2021 for Wave 3 (where data were largely collected in July/August 2021) and 2022 for Wave 4 (when data were largely collected in September-November 2022). If annual health checks are carried out throughout the calendar year, then fewer people at Wave 3 may have had an annual health check by the time of their interview/survey than people in Wave 4 who were interviewed or surveyed later in the calendar year.

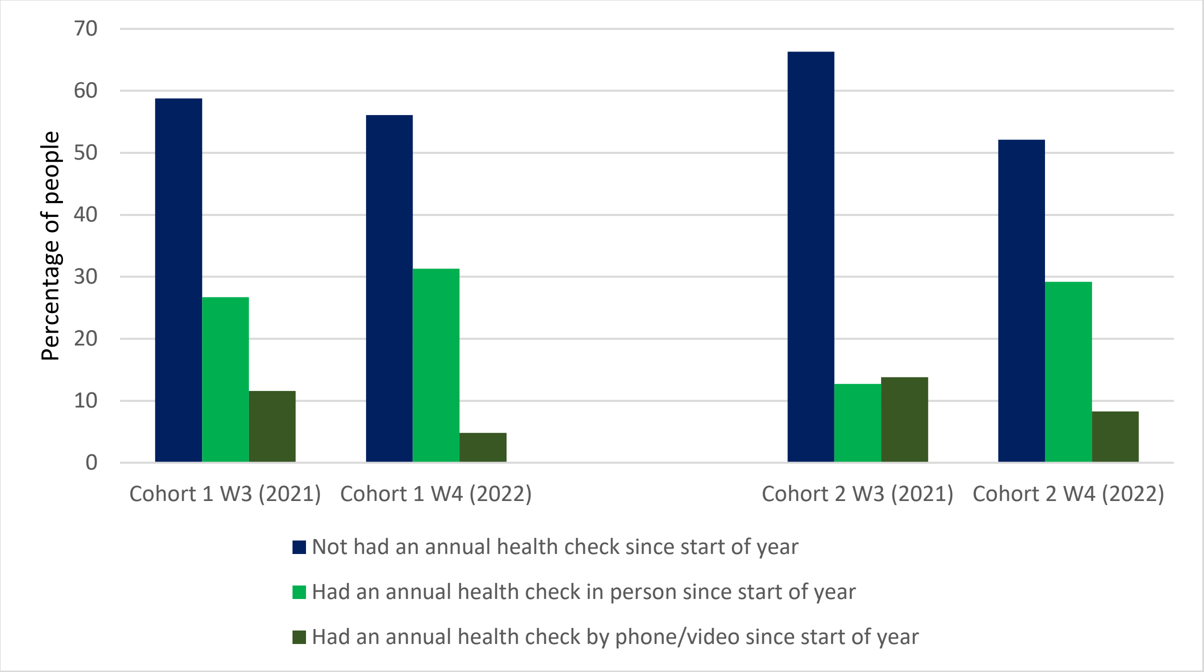

Figure 2.14. Since the start of this year (2021 for Wave 3, 2022 for Wave 4), have you had your annual health check? (percentage of all people in Cohort 1 and Cohort 2)

For all people in Cohort 1, 56% had not had an annual health check so far in 2022 (Wave 4), compared to 59% of people in 2021 (Wave 3). By Wave 4, almost a third of people in Cohort 1 (31%) had had an annual health check in person (compared to 27% of people at Wave 3), with a further 5% having an annual health check by ‘phone or video link (compared to 12% of people at Wave 3). At Wave 4, three-quarters of people in Cohort 1 who had had an annual health check (75%) rated the check as good.

For all people in Cohort 2, 52% had not had an annual health check so far in 2022 (Wave 4), compared to 66% of people in 2021 (Wave 3). By Wave 4, almost a third of people in Cohort 2 (29%) had had an annual health check in person (compared to 13% of people at Wave 3), with a further 8% having an annual health check by ‘phone or video link (compared to 14% of people at Wave 3). At Wave 4, less than half of family carers or support workers (44%) rated the check as good.

2.3.7. Prescribed medication

Across all four waves, we asked if people in Cohort 1 and Cohort 2 were taking any medications, and if they were having difficulty/were unable to get the medications they needed.

Across all four waves, a substantial and consistent majority of people in Cohort 1 (76%-79%) and Cohort 2 (79%-83%) were taking medications. From Waves 1 to 3, the number of people reported to being having difficulties in getting medications were extremely low (0-1% Cohort 1; 0-1% Cohort 2). By Wave 4, the number of people in Cohort 1 (11%) and Cohort 2 (23%) reported to have difficulty in getting the medications they needed had increased substantially.

2.4. Wellbeing and mental health

We asked about the wellbeing of people with learning disabilities in the weeks before the interview (Cohort 1) or survey (Cohort 2).

We asked participants in Cohort 1 in all four waves about their COVID-19-related worries in the week before the interview or survey, using an adapted version of the Pandemic Anxiety Scale[9]. Data related to all seven items in this scale are displayed in Figure 2.15.

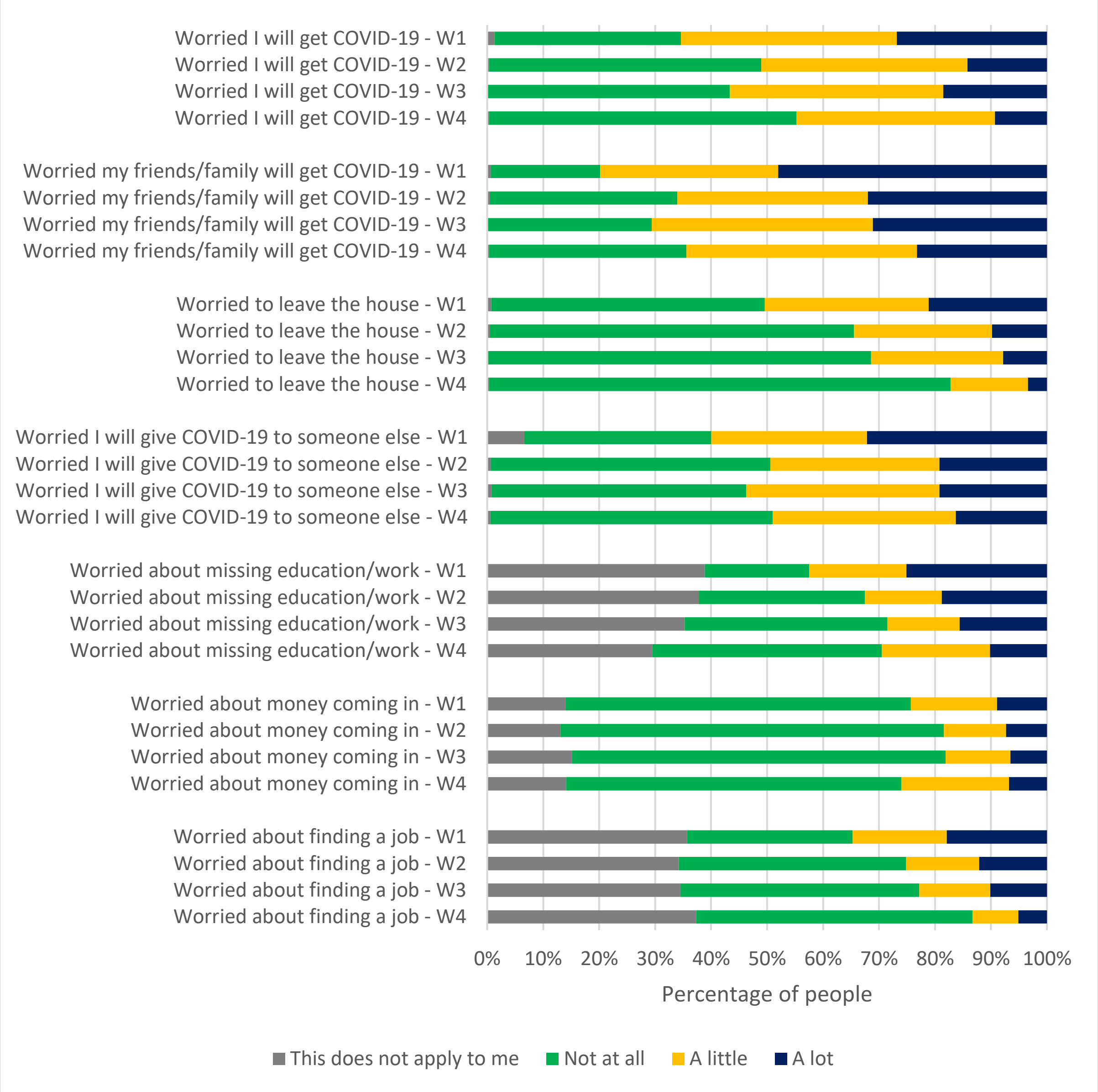

Figure 2.15. Questions on the Pandemic Anxiety Scale (Elroy et al., 2020) at Waves 1, 2, 3 and 4 (Cohort 1 only)

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[9] 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.

Overall, there is a trend for worries related to the COVID-19 pandemic to continue to reduce into Wave 4. However, it is worth noting that even by Wave 4 considerable numbers of people in Cohort 1 continued to be worried about friends and family getting COVID-19 (23% of people at Wave 4 worried a lot; 74% worried at least a little), worried about giving COVID-19 to someone else (16% worried a lot; 49% worried at least a little), and/or worried about getting COVID-19 themselves (9% worried a lot; 45% worried at least a little).

Worrying at least a little about the amount of money coming in increased from Wave 3 (18%) to Wave 4 (26%). One in seven people in Cohort 1 at Wave 4 (14%) said that this question did not apply to them, presumably because they no control over financial aspects of their lives.

We also asked some general questions about the wellbeing of people with learning disabilities in the last four weeks to both cohorts, and these data are presented in Figures 2.16 and 2.17.

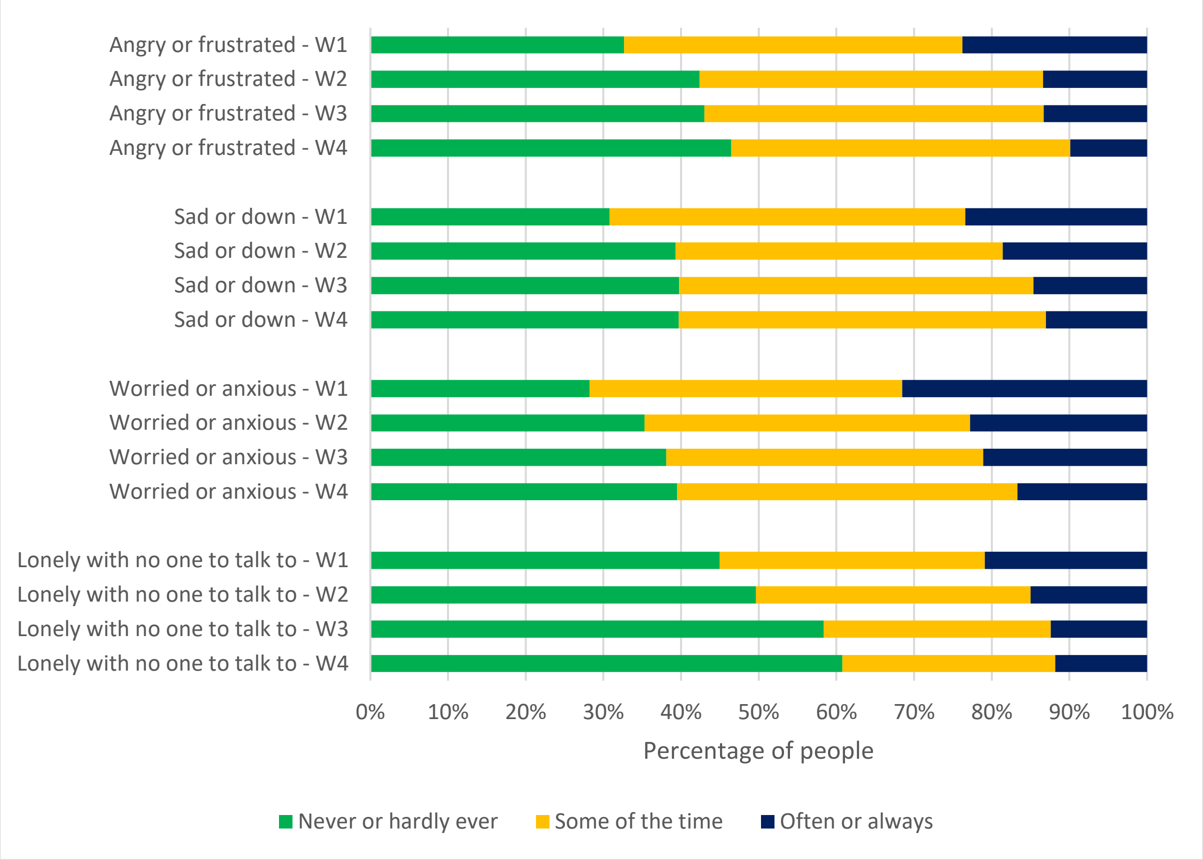

Figure 2.16. How people with learning disabilities have felt over the last four weeks (Cohort 1) – Waves 1, 2, 3 and 4

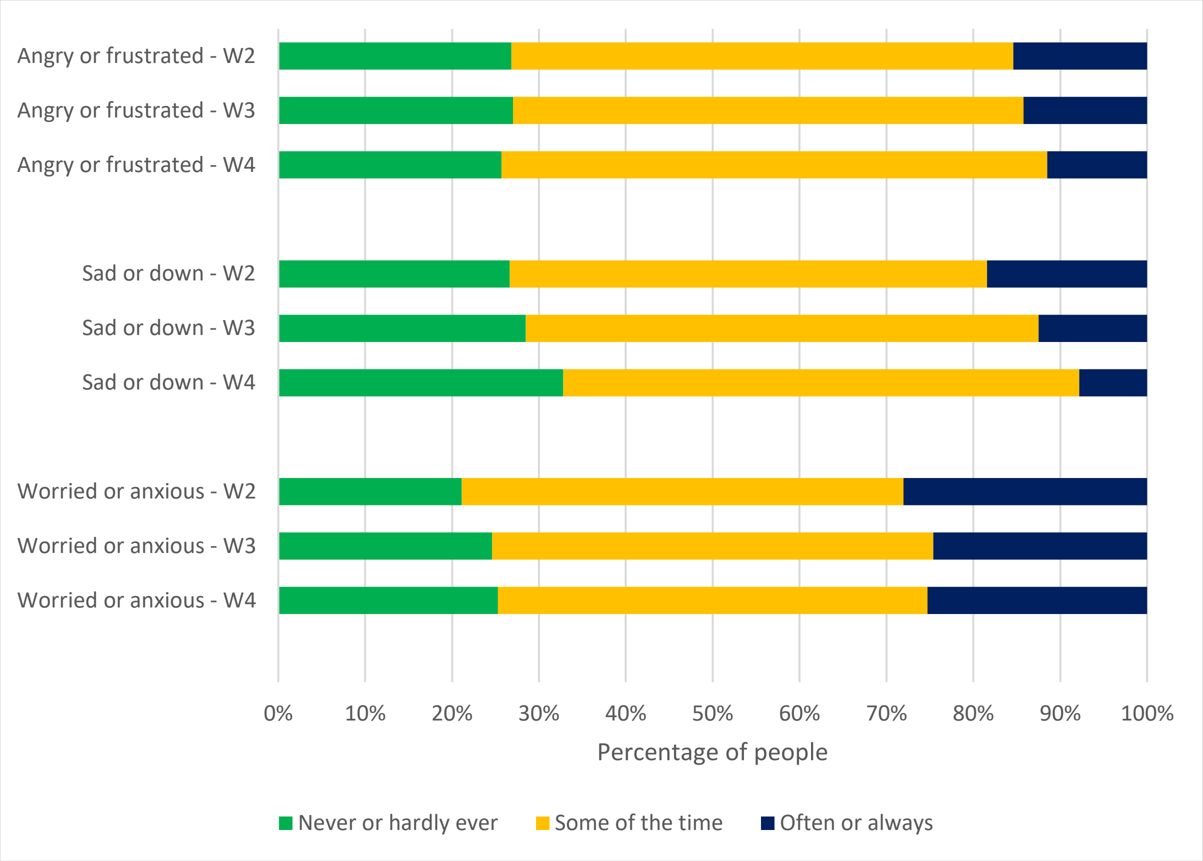

Figure 2.17. How people with learning disabilities have felt in the last four weeks (Cohort 2) – Waves 2, 3 and 4

For people in Cohort 1, these indicators of well-being continued to improve by Wave 4, although improvements over the more than a year from Wave 3 to Wave 4 were small compared to improvements from Wave 1 (Jan/Feb 2021, in a national lockdown) to Wave 3 (July/Aug 2021, when COVID-19 public health protection measures had largely ceased). By Wave 4, in Cohort 1 well over a third of people (39%) said they felt lonely at least some of the time (12% often or always), almost two thirds (61%) said they felt worried or anxious at least some of the time (17% often or always), almost two thirds (60%) said they felt sad or down at least some of the time (13% often or always), and over half (54%) said they felt angry or frustrated at least some of the time (10% often or always).

Family carers or support workers of people in Cohort 2 reported generally poorer wellbeing for the person they were supporting/caring for than people in Cohort 1, with small improvements from Wave 2 to Wave 4. By Wave 4, three-quarters of people in Cohort 2 (75%) were reported to be worried or anxious at least some of the time (25% often or always), over two thirds (69%) were reported to be sad or down at least some of the time (8% often or always), and almost three quarters (74%) were reported to be angry or frustrated at least some of the time (12% often or always). At Wave 1, over 60% of family carers or support workers reported that the wellbeing of people in Cohort 2 on all these indicators had worsened since the beginning of the first COVID-19 lockdown.

In both cohorts, at Wave 3 and Wave 4 we asked if people with learning disabilities were receiving any support when they are feeling sad, worried, or angry, with a small number of response options changing for Cohort 2 from Wave 3 to Wave 4. These data are displayed in Table 2.5 below.

Table 2.5. Support for people with learning disabilities when they are feeling sad, worried or angry (Select all that apply) – Wave 3 and 4

	Cohort 1		**Cohort 2**	
	Wave 3	**Wave 4**	**Wave 3**	**Wave 4**
Yes, from a mental health professional	8%	10%	7%	6%
Yes, from someone paid to support them	36%	36%	23%	31%
Yes, from family	45%	51%	50%	62%
Yes, from friends	26%	25%	5%	7%
Yes, from mental health resources (online, videos, information, etc.)	3%	2%	1%	1%
Have not been sad, worried, or angry	18%	16%	n/a	10%
Not applicable	n/a	n/a	14%	n/a
Did not seek or get help	11%	9%	n/a	14%
Don’t know	1%	<1%	2%	6%
Prefer not to say	0%	0%	0%	2%

At Wave 4, 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, at Wave 4 the most frequently reported sources of support were family (51%), support workers (36%), and friends (25%), broadly similar to support received at Wave 3. In Cohort 2, at Wave 4 the most frequently reported sources of support were family (62%) and support workers (31%). Although there were some changes in response options for Cohort 2 from Wave 3 to Wave 4, it possible that more people in Cohort 2 were receiving support from support workers and from family at Wave 4 compared to Wave 3.

Finally, at Wave 4 we asked people in Cohort 1 how self-confident they were, with a substantial majority of people (84%) saying they were confident or very confident. We asked this question to family carers and support workers about people in Cohort 2; 41% of people in Cohort 2 were reported to be confident or very confident.

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 at Wave 4. These are:

- staying in touch with family and friends,
- whether there are visitor restrictions where people live, and
- how people are using technology (digital inclusion).

2.5.1. Staying in touch with family and friends

At Wave 4, we asked both cohorts whether and how often people with learning disabilities saw family (beyond family members they live with) and friends, with the findings shown in Tables 2.6 and 2.7 below.

Table 2.6. Whether and how often people see family (apart from family members people live with) – Wave 4

	Cohort 1	**Cohort 2**
Do you ever see anyone in your family?		
Yes	89%	90%
If yes, how often do you see them?		
Every day/nearly every day	15%	11%
A couple of times a week	17%	23%
Every week or nearly every week	33%	42%
About monthly	17%	13%
A few times a year	18%	13%

Table 2.7. Whether and how often people see friends – Wave 4

	Cohort 1	**Cohort 2**
Do you have friends you like to talk to or do things with?		
Yes	91%	47%
If yes, how often do you see them?		
Every day/nearly every day	23%	13%
A couple of times a week	34%	23%
Every week or nearly every week	29%	35%
About monthly	8%	17%
A few times a year	7%	13%

The vast majority of people in Cohort 1 (89%) and Cohort 2 (90%) stayed in touch with family members (beyond family members they were living with), with most people in both cohorts in contact with family at least weekly (65% Cohort 1; 76% Cohort 2).

The vast majority of people in Cohort 1 (91%) said they had friends they liked to talk or do things with, compared to Cohort 2 where just under half of people (47%) were reported to have friends. Among those who did have friends, most people in both cohorts reported being in contact with friends at least weekly (86% Cohort 1; 71% Cohort 2).

2.5.2. Visitor restrictions

Participants in both cohorts who lived in housing organised by services were asked about whether there had been any visitor restrictions in the last four weeks where the person with learning disabilities lived. For people in Cohort 1, 12% of people living in housing organised by services reported rules about people visiting them in their home at Wave 4, usually involving COVID-19 testing or visitors keeping a distance from others the person is sharing a house with. This is a decrease compared to Wave 3, where 33% of people experienced restrictions on visits to their homes.

For people in Cohort 2, 26% of people living in housing organised by services were reported by family carers or support workers at Wave 4 to have rules about visiting, largely around COVID-19 testing and wearing facemasks when visiting. Again, this was a decrease compared to Wave 3 (56% of people).

2.5.3. Digital inclusion

We were interested to know what the continued digital inclusion of people with learning disabilities was like as more people returned to more socially active lives from Wave 3 to Wave 4.

By Wave 4, the vast majority of people in Cohort 1 still used the internet at home (88% at Wave 4 compared to 92% at Wave 3). At Wave 4 we also asked people in Cohort 1 whether they had had any training about how to do things online in 2022; 15% of people had had such training, 29% felt confident enough online not to need training, 21% would like training and 32% did not want training.

At Wave 4 we also asked family carers and support workers about internet usage among people in Cohort 2. Just under two-thirds of people in Cohort 2 (63%) were reported to use the internet at home, for almost a third of people (31%) there was internet where they lived but they did not use it.

We also asked about what people who had the internet where they lived used it for during Wave 4, asking an extended range of questions compared to Wave 3. These data are displayed in Figure 2.18 below.

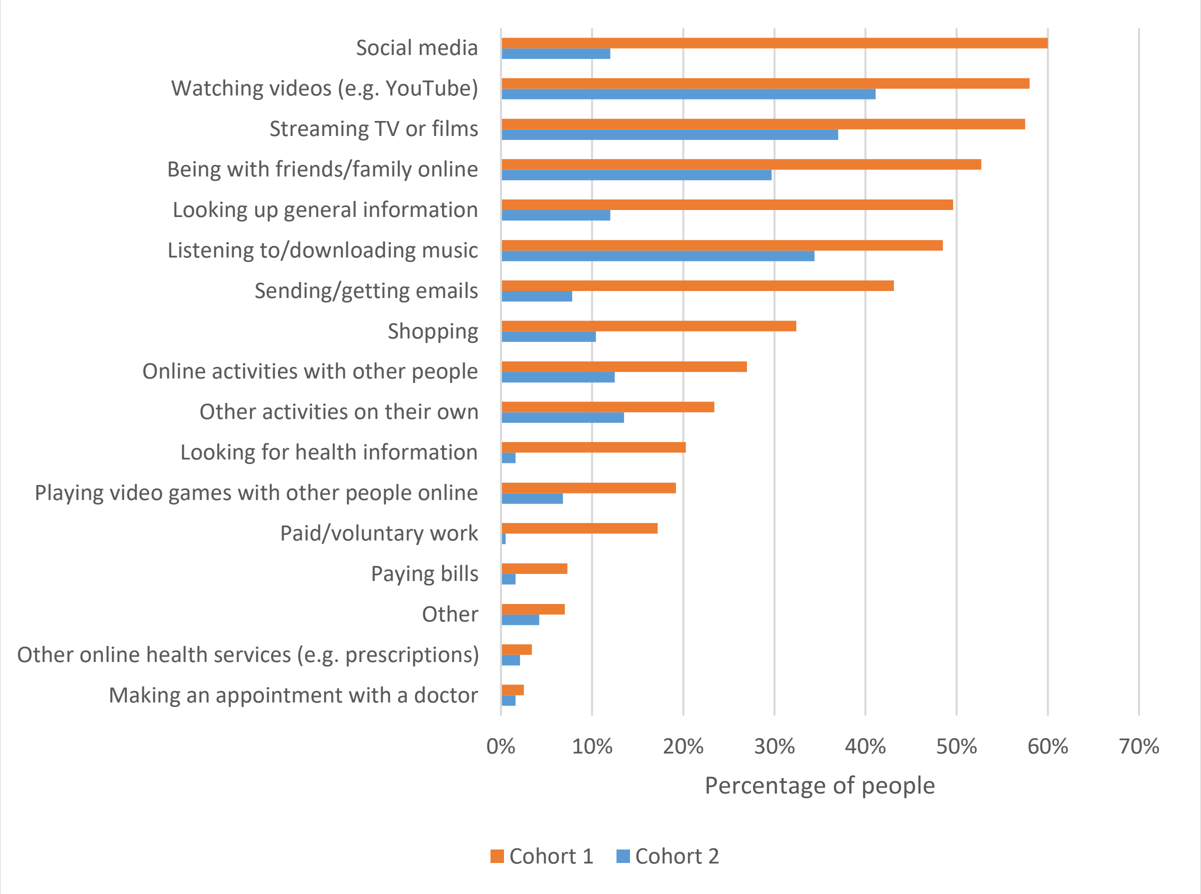

Figure 2.18. What people with learning disabilities currently use the internet for – Wave 4

The most common uses of the internet for people in Cohort 1 at Wave 4 were social media (60% of people using the internet), watching videos (58%), streaming TV/films (58%) and being with friends/family online (53%), although a wide variety of broadly leisure uses were reported by people in Cohort 1. Among Cohort 1, 17% of people were using the internet for paid or voluntary work purposes. Using the internet for such practical reasons as paying bills or arranging health appointments was much less common among people in Cohort 1 (<10% of people).

Much smaller proportions of people in Cohort 2 were generally reported to use the internet for all purposes compared to people in Cohort 1. People in Cohort 2 most commonly used the internet for watching videos (41% of people using the internet), streaming TV/films (37%), listening to/downloading music (34%) and being with friends/family online (30%).

We asked about nine of these online activities in Wave 3. For most of these online activities similar proportions of people in both cohorts were using the internet for these purposes at Wave 3 and Wave 4. There were three online activities where internet usage reduced from Wave 3 to Wave 4: being with friends/family online (64% Wave 3 vs 53% Wave 4 Cohort 1; 48% Wave 3 vs 30% Wave 4 Cohort 2); online activities with other people (49% Wave 3 vs 27% Wave 4 Cohort 1; 25% Wave 3 vs 13% Wave 4 Cohort 2); and online activities on their own (54% Wave 3 vs 23% Wave 4 Cohort 1; 26% Wave 3 vs 14% Wave 4 Cohort 2). This is possibly due to face-to-face contact returning over time.

2.6 Sources of support

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

2.6.1. Access to support

Social workers. Figure 2.19 below presents data about whether people with learning disabilities in Cohort 1 and Cohort 2 at Waves 2, 3 and 4 had been in contact with a social worker in the four weeks before each interview/survey.

In both cohorts across Waves 2, 3 and 4, just over three quarters of people (75%-78%) were consistently reported to not have been in contact with a social worker in the last four weeks. Among those people at Wave 4 who had not been in contact with a social worker in the last four weeks, 42% of people in Cohort 1 and 59% of people in Cohort 2 used to see a social worker but had not seen one in the last four weeks. At Wave 1, over a third of people in Cohort 1 (37%) and Cohort 2 (37%) were reported to have regular contact with a social worker before the start of the COVID-19 pandemic.

For both cohorts who did have contact with a social worker in the last four weeks, there is a trend over time for more in person contact and less ‘phone/video contact. By Wave 4, 57% of those people in Cohort 1 who had been in contact with a social worker in the last four weeks had met their social worker in person. At Wave 4, well over three quarters of all the people in Cohort 1 who answered this question (82%) preferred to meet their social worker in person, compared to smaller numbers preferring to be in contact by ‘phone/video (10%) or saying that it would depend/they did not mind how (8%).

By Wave 4, 75% of those people with learning disabilities in Cohort 2 who had seen a social worker in the last four weeks had met their social worker in person. At Wave 4, 58% of family carers or support workers of people in Cohort 2 said that the preference would be to meet the social worker in person, with 22% preferring ‘phone/video and 20% saying that it would depend/they did not mind how.

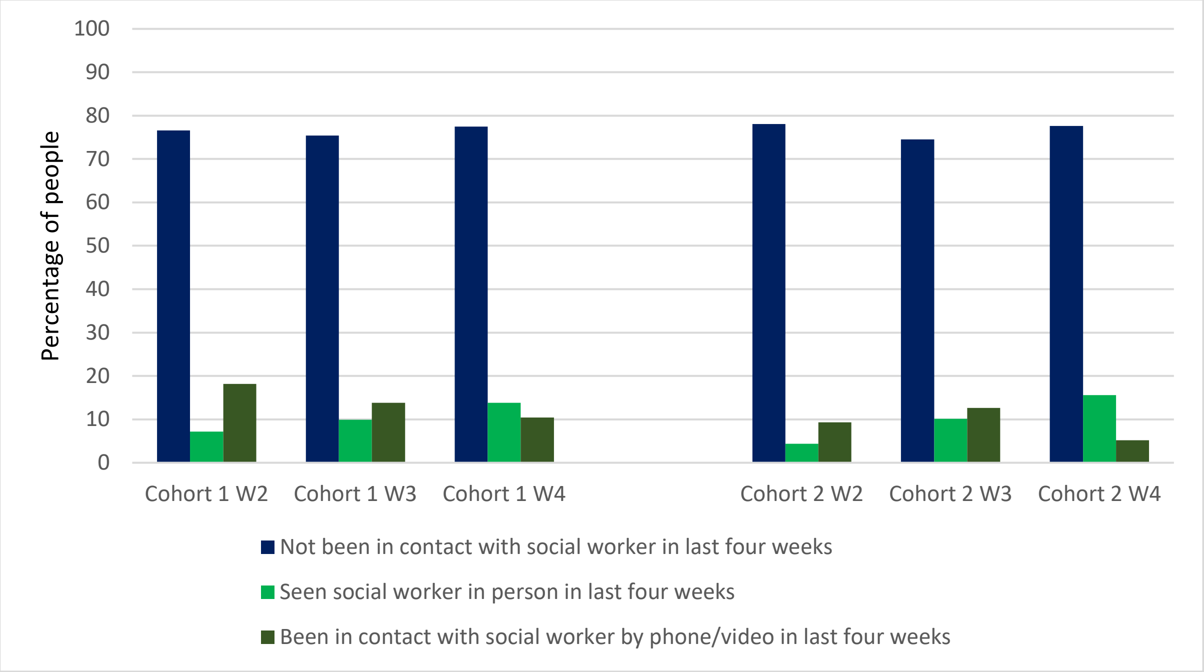

Figure 2.19. Contact with social workers in the last four weeks for people with learning disabilities: Waves 2, 3 and 4

Day services. Figure 2.20 below presents data about whether people with learning disabilities in Cohort 1 and Cohort 2 at Waves 2, 3 and 4 had been using day services in the four weeks before each interview/survey.

In Cohort 1, the proportion of people not using any form of day service decreased slightly from 78% at Wave 2 to 74% at Wave 4. At Wave 1, 37% of people in Cohort 1 said that they used to regularly attend a day service before the COVID-19 pandemic. By Wave 4, small numbers of people in Cohort 1 were not using day services because the service was closed (2% of all people in Cohort 1 at Wave 4, compared to 6% at Wave 3) or not using them because they could not or did not want to use the service at the moment (1% Wave 4; 2% Wave 3).

In Cohort 2, the proportion of people not using any form of day service decreased from 68% at Wave 2 to 55% at Wave 4. At Wave 1, 61% of people in Cohort 2 had been reported to regularly use a day service before the COVID-19 pandemic. By Wave 4, the proportion of all people in Cohort 2 not using a day service because it was closed had dropped (3% Wave 4; 12% Wave 3), although there were still some people in Cohort 2 who could not or did not want to use a day service that was open (7% Wave 4; 8% Wave 3).

For both cohorts, by Wave 4 almost all day services being used were places people went to, rather than online activities at home.

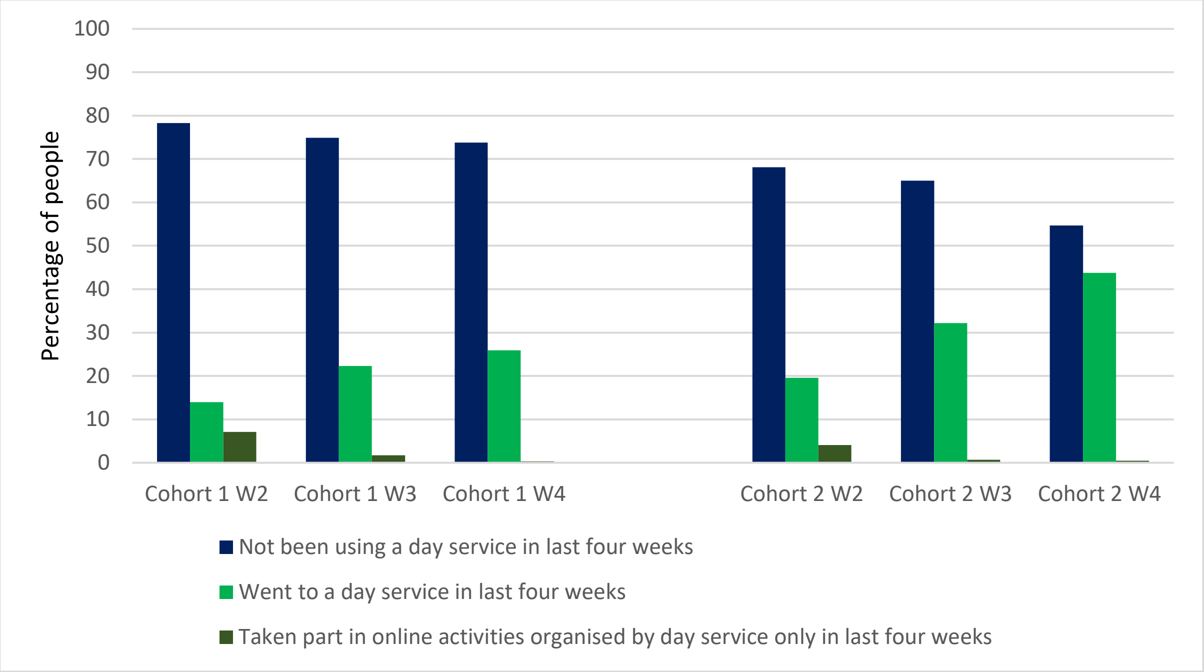

Figure 2.20. Use of day services in the last four weeks for people with learning disabilities: Waves 2, 3 and 4

At Waves 3 and 4, we also asked how many days a week people were using a day service – the findings are in Table 2.8 below. For Cohort 1, at Wave 4 almost two thirds of those people using a day service (65%) were using the service for 2 days a week or less, with fewer people at Wave 4 using a day service for 5+ days a week than at Wave 3 (8% Wave 4; 14% Wave 3).

For Cohort 2, at Wave 4 just over a third of those people using a day service (37%) were using the service for 2 days a week or less, with more people at Wave 4 using a day service for 4 days or more a week (45% Wave 4; 31% Wave 3).

Table 2.8: Number of days per week people are using a day service: Waves 3 and 4

	Cohort 1		**Cohort 2**	
	Wave 3	**Wave 4**	**Wave 3**	**Wave 4**
Less than 1 day a week	8%	9%	16%	10%
1 day a week	27%	26%	19%	12%
2 days a week	30%	30%	15%	15%
3 days a week	10%	15%	19%	19%
4 days a week	12%	12%	15%	22%
5+ days a week	14%	8%	16%	23%

Community activities. Figure 2.21 below presents data about whether people with learning disabilities in Cohort 1 and Cohort 2 at Waves 2, 3 and 4 had been going out to community activities in the four weeks before each interview/survey.

In Cohort 1, the proportion of people not taking part in any form of community activity decreased from 48% at Wave 2 to 37% at Wave 4. At Wave 1, 86% of people in Cohort 1 said that they used to regularly go out to community activities before the COVID-19 pandemic.

In Cohort 2, the proportion of people not taking part in any form of community activity decreased from 83% at Wave 2 to 41% at Wave 4. At Wave 1, 84% of people in Cohort 2 had been reported to regularly go out to community activities before the COVID-19 pandemic.

For both cohorts, by Wave 4 almost all community activities were activities that people went out to, rather than online activities at home.

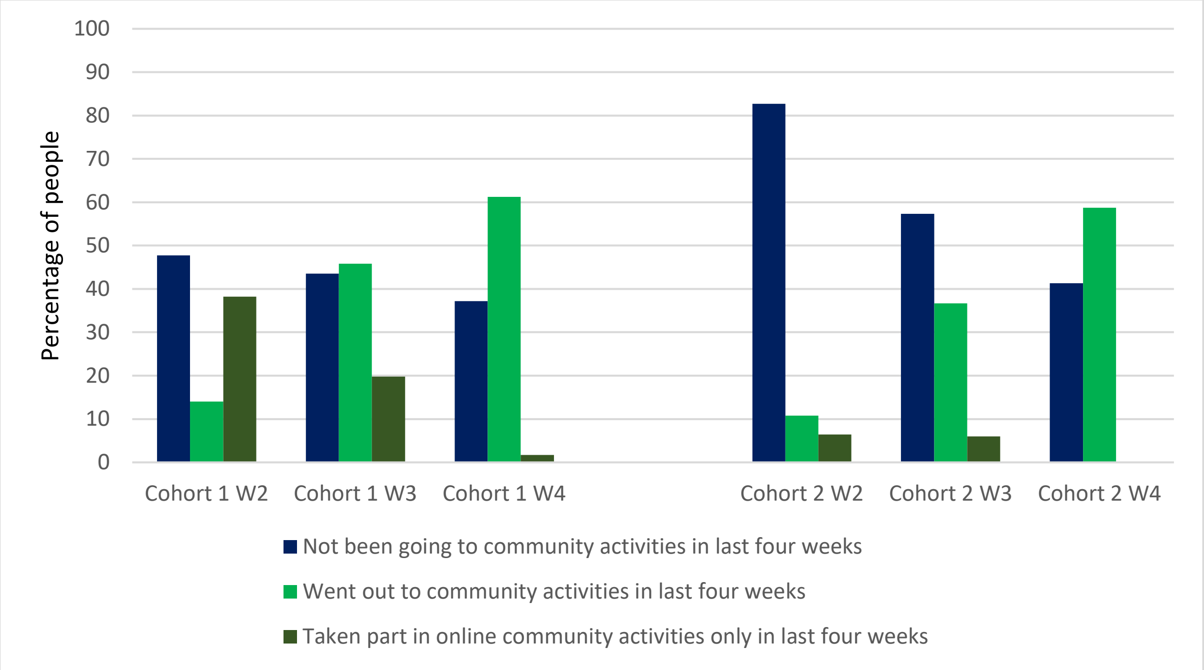

Figure 2.21. Taking part in community activities in the last four weeks for people with learning disabilities: Waves 2, 3 and 4

At Waves 3 and 4, we also asked how many days a week people were taking part in community activities – the findings are in Table 2.9 below. For Cohort 1, at Wave 4 almost two thirds of those people taking part in community activities (66%) were taking part for 2 days a week or less, with little change from Wave 3 to Wave 4. Similarly, for Cohort 2 at Wave 4 just over two thirds of those people taking part in community activities (68%) were taking part for 2 days a week or less, again with little change from Wave 3 to Wave 4.

Table 2.9: Number of days per week people are taking part in community activities: Waves 3 and 4

	Cohort 1		Cohort 2	
	Wave 3	**Wave 4**	**Wave 3**	**Wave 4**
Less than 1 day a week	21%	19%	23%	24%
1 day a week	31%	30%	15%	14%
2 days a week	19%	17%	29%	30%
3 days a week	10%	11%	15%	11%
4 days a week	6%	7%	8%	6%
5+ days a week	13%	16%	11%	15%

Going out of the house with personal assistants/support workers. Figure 2.22 below presents data about whether people with learning disabilities in Cohort 1 and Cohort 2 at Waves 2, 3 and 4 had been going out of the house with PAs/support workers in the four weeks before each interview/survey.

In Cohort 1, the proportion of people not going out with a PA/support worker was 51% at Wave 2 and 56% at Wave 4. At Wave 1, 50% of people in Cohort 1 said they used to regularly go out with PAs/support workers before the COVID-19 pandemic.

In Cohort 2, the proportion of people not going out with a PA/support worker was 44% at Wave 2 and 41% at Wave 4. At Wave 1, 76% of people in Cohort 2 had been reported to regularly go out with PAs/support workers before the COVID-19 pandemic.

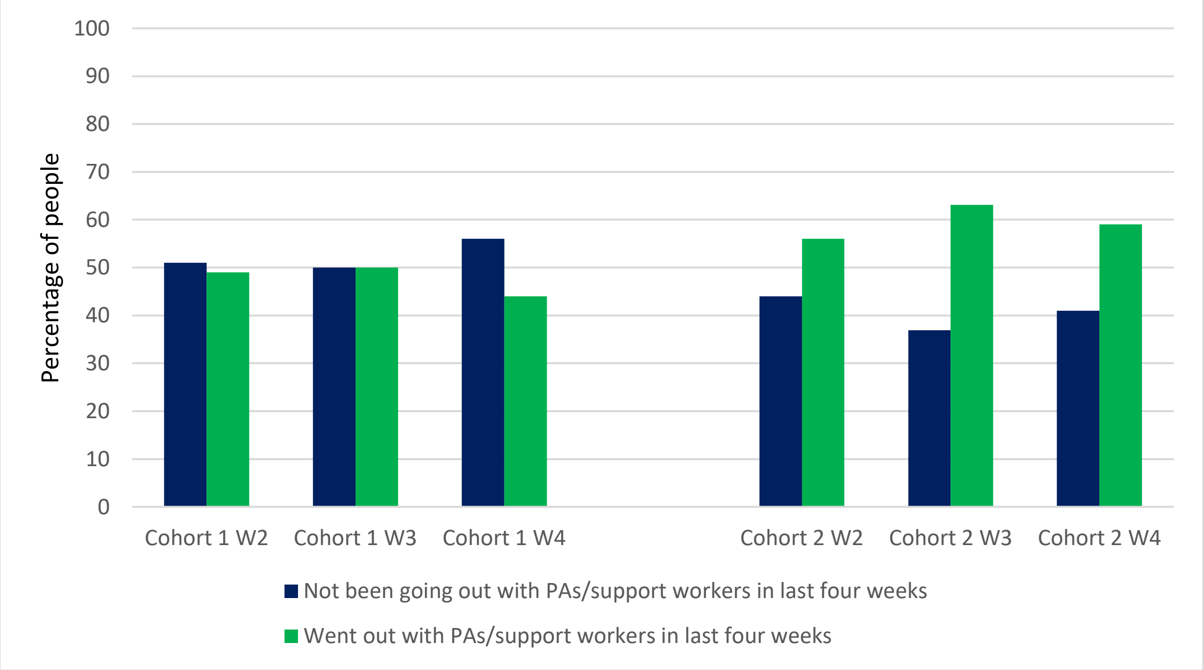

Figure 2.22. Taking part in community activities in the last four weeks for people with learning disabilities: Waves 2, 3 and 4

At Waves 3 and 4, we also asked how many days a week people were going out with PAs/support workers – the findings are in Table 2.10 below. For both cohorts there were small increases in the proportion of people going out with PAs for 4 days or more per week (Cohort 1: 31% Wave 3 to 37% Wave 4; Cohort 2: 42% Wave 3 to 49% Wave 4).

Table 2.10: Number of days per week people are going out with PAs/support workers: Waves 3 and 4

	Cohort 1		**Cohort 2**	
	Wave 3	**Wave 4**	**Wave 3**	**Wave 4**
Less than 1 day a week	12%	8%	24%	17%
1 day a week	23%	25%	11%	12%
2 days a week	19%	19%	11%	14%
3 days a week	16%	11%	13%	9%
4 days a week	6%	7%	12%	14%
5+ days a week	25%	30%	30%	35%

Further education. At Wave 4, 8% of people in Cohort 1 had attended further education outside their home in the last four weeks; a further 1% had engaged in online further education activities at home and a further 1% said they should be going to further education but hadn’t in the last four weeks.

At Wave 4, 13% of people in Cohort 2 had attended further education outside their home in the last four weeks; a further 2% had engaged in online further education activities at home and for a further 2% it was reported that they should be going to further education but hadn’t in the last four weeks.

Comparisons with earlier waves are difficult due to seasonal factors (Wave 3 was largely conducted in educational summer holidays) and younger adult participants ageing over the course of the research project.

Short breaks/respite. Figure 2.23 below presents data about whether those people with learning disabilities living with their families in Cohort 1 and Cohort 2 at Waves 2, 3 and 4 had gone to a short break/respite service in the four weeks before each interview/survey.

In Cohort 1, the proportion of people living with their families going to a short break/respite service in the last four weeks increased between Wave 2 (6%) and Waves 3 (16%) and 4 (13%). At Wave 1, 27% of people in Cohort 1 living with their families said that they used to regularly go to short break/respite services before the COVID-19 pandemic.

In Cohort 2, the proportion of people living with their families going to a short break/respite service in the last four weeks increased over time, from 10% at Wave 2 through 14% at Wave 3 to 27% at Wave 4. At Wave 1, 39% of people in Cohort 2 living with their families had been reported to regularly go to short break/respite services before the COVID-19 pandemic.

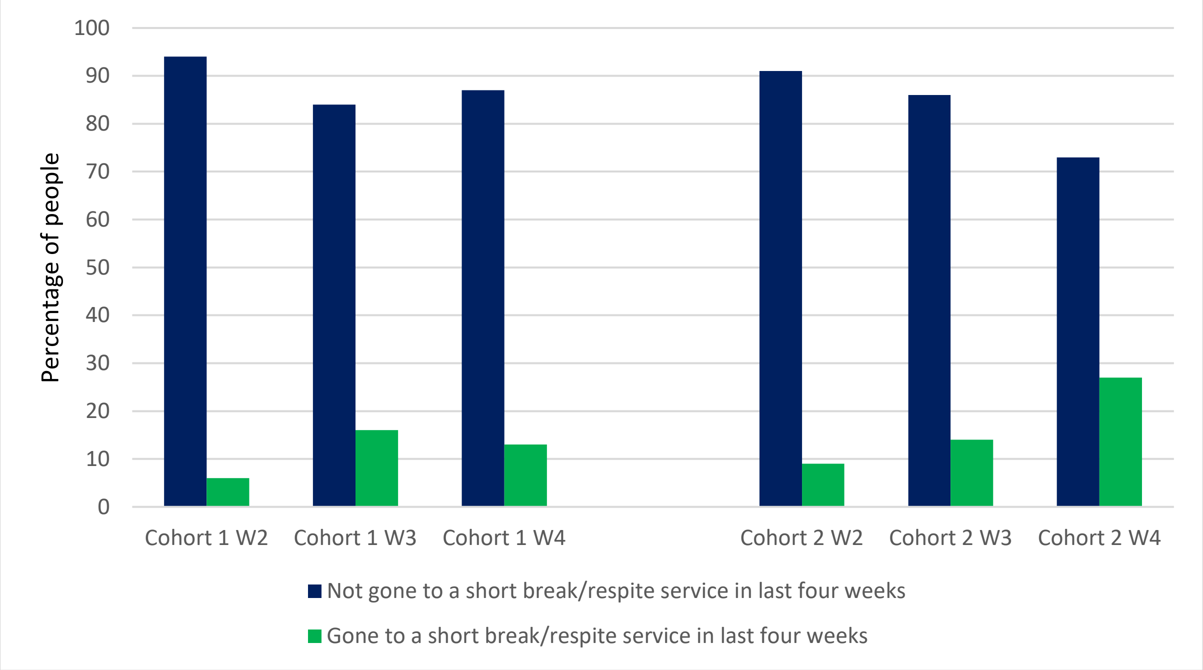

Figure 2.23. For those people living with families, going to a short break/respite service in the last four weeks: Waves 2, 3 and 4

Activities organised by self-advocacy groups. At Wave 4, just over a third of people in Cohort 1 (34%) had been involved in activities organised by a self-advocacy group in the last four weeks; the figure was lower for people in Cohort 2 (13%). In both Cohorts, more people took part in activities in person (31% Cohort 1; 9% Cohort 2) than online activities (12% Cohort 1; 2% Cohort 2) – people could select both options if they were involved in both in person and online activities.

Personal assistants/support workers helping at home. Figure 2.24 below presents data about whether people with learning disabilities in Cohort 1 and Cohort 2 at Waves 2, 3 and 4 had been getting help at home from PAs/support workers in the four weeks before each interview/survey.

In Cohort 1, the proportion of people not getting help at home from PAs/support workers decreased from 54% at Wave 2 to 49% at Wave 4. At Wave 1, 56% of people in Cohort 1 said that they used get help at home from PAs/support workers before the COVID-19 pandemic.

In Cohort 2, the proportion of people not getting help at home from PAs/support workers stayed consistent over time (56% Wave 2; 57% Wave 3; 55% Wave 4). At

Wave 1, 60% of people in Cohort 2 had been reported to regularly get help at home from PAs/support workers before the COVID-19 pandemic.

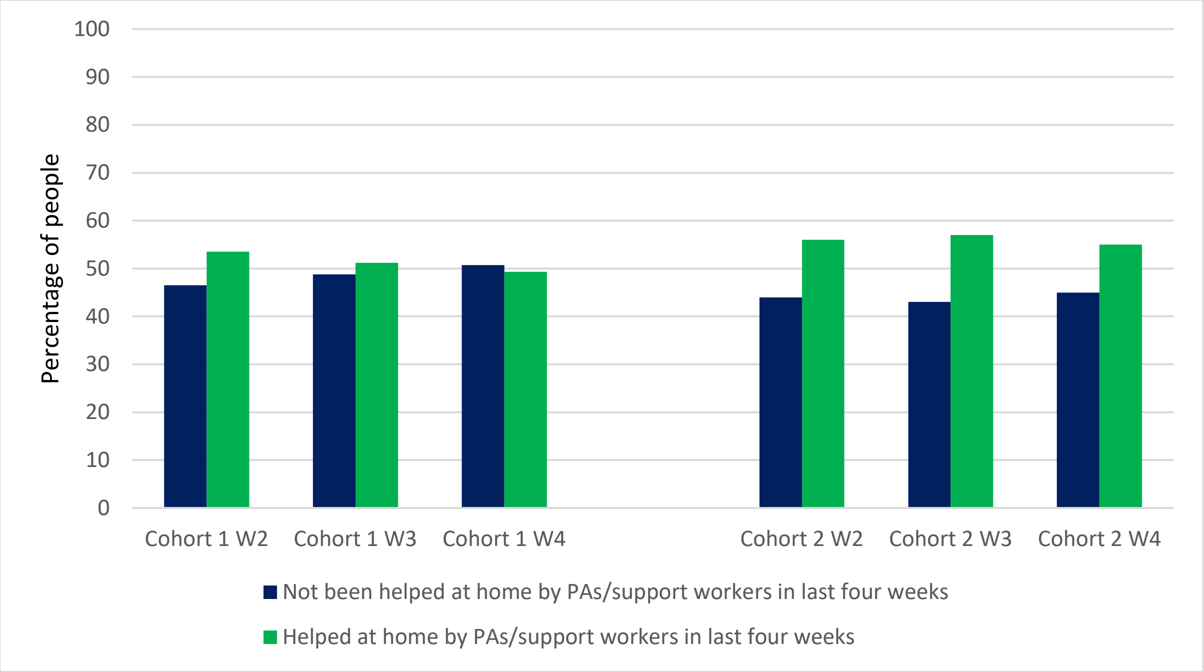

Figure 2.24. People with learning disabilities getting help at home from PAs/support workers in the last four weeks: Waves 2, 3 and 4

At Waves 3 and 4, we also asked how many days a week people were getting help from PAs/support workers – the findings are in Table 2.11 below. For both cohorts, among those getting support at home, at both Wave 3 and Wave 4 a substantial majority of people (73%-74% Cohort 1; 65%-70% Cohort 2) were getting support for 5 or more days a week.

Table 2.11: Number of days per week people are getting help at home from PAs/support workers: Waves 3 and 4

	Cohort 1		**Cohort 2**	
	Wave 3	**Wave 4**	**Wave 3**	**Wave 4**
Less than 1 day a week	3%	3%	7%	8%
1 day a week	8%	10%	8%	4%
2 days a week	7%	7%	11%	6%
3 days a week	4%	6%	4%	6%
4 days a week	3%	2%	5%	7%
5+ days a week	74%	73%	65%	70%

At Wave 4, we also asked some questions relating to anyone getting support in their home from PAs/support workers, whether people were living alone, with other people with learning disabilities, or with their family. Almost a quarter of people in Cohort 1 (22%) and over a third of family carers/support workers in Cohort 2 (36%) reported that a PA or support worker helping the person at home had left their job in the last four weeks.

For a substantial majority of people in Cohort 1 (81%) and Cohort 2 (70%), all or most PAs/support workers were reported to know the person with learning disabilities well. For relatively few people in Cohort 1 (2%) and Cohort 2 (8%), most or all PAs/support workers were reported not to know the person well.

A substantial majority of people in Cohort 1 (86%) and Cohort 2 (73%) were reported to like most or all of the PAs/support workers who supported them at home. Almost no-one (2% Cohort 1; 0% Cohort 2) was reported to not like most or all of the PAs/support workers who supported them at home.

Finally, at Wave 4 we asked family carers of people in Cohort 2 whether in the last four weeks they had had to step in and carry out work previously done by a paid support worker – close to half of family carers (45%) said this was the case.

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:

- about the reasons why people with learning disabilities go outside 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. Leaving the house and getting around

We asked about the reasons people with learning disabilities left their home during the week before the interview or survey, at each wave. The reasons people with learning disabilities in both cohorts left their houses at each wave are presented in Figure 2.25 for Cohort 1 and Figure 2.26 for Cohort 2. Most questions were asked consistently across all four waves, but a small number of questions were added in later waves.

Differences in responses to these questions over time are likely to reflect multiple factors, such as changes in COVID-19 public health protection measures, seasonal differences, and differences related to the cost of living.

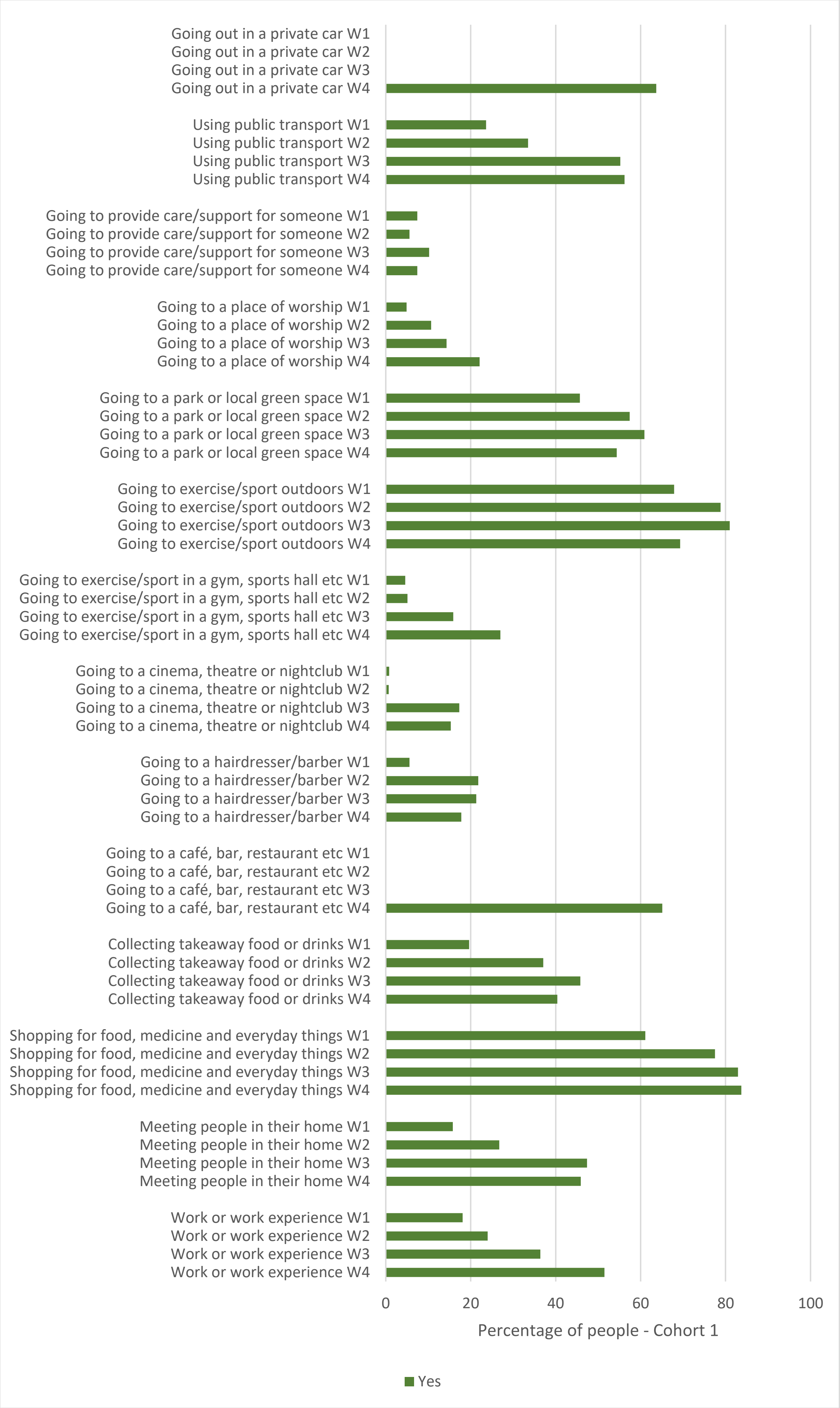
Going out in a private car W1
Going out in a private car W2
Going out in a private car W3
Going out in a private car W4
Using public transport W1
Using public transport W2
Using public transport W3
Using public transport W4
Going to provide care/support for someone W1
Going to provide care/support for someone W2
Going to provide care/support for someone W3
Going to provide care/support for someone W4
Going to a place of worship W1
Going to a place of worship W2
Going to a place of worship W3
Going to a place of worship W4
Going to a park or local green space W1
Going to a park or local green space W2
Going to a park or local green space W3
Going to a park or local green space W4
Going to exercise/sport outdoors W1
Going to exercise/sport outdoors W2
Going to exercise/sport outdoors W3
Going to exercise/sport outdoors W4
Going to exercise/sport in a gym, sports hall etc W1
Going to exercise/sport in a gym, sports hall etc W2
Going to exercise/sport in a gym, sports hall etc W3
Going to exercise/sport in a gym, sports hall etc W4
Going to a cinema, theatre or nightclub W1
Going to a cinema, theatre or nightclub W2
Going to a cinema, theatre or nightclub W3
Going to a cinema, theatre or nightclub W4
Going to a hairdresser/barber W1
Going to a hairdresser/barber W2
Going to a hairdresser/barber W3
Going to a hairdresser/barber W4
Going to a café, bar, restaurant etc W1
Going to a café, bar, restaurant etc W2
Going to a café, bar, restaurant etc W3
Going to a café, bar, restaurant etc W4
Collecting takeaway food or drinks W1
Collecting takeaway food or drinks W2
Collecting takeaway food or drinks W3
Collecting takeaway food or drinks W4
Shopping for food, medicine and everyday things W1
Shopping for food, medicine and everyday things W2
Shopping for food, medicine and everyday things W3
Shopping for food, medicine and everyday things W4
Meeting people in their home W1
Meeting people in their home W2
Meeting people in their home W3
Meeting people in their home W4
Work or work experience W1
Work or work experience W2
Work or work experience W3
Work or work experience W4
0
20
40
60
80
100
Percentage of people - Cohort 1
Yes

Figure 2.25. Reasons that people with learning disabilities left their house in the last week – Cohort 1 – Waves 1, 2, 3 and 4

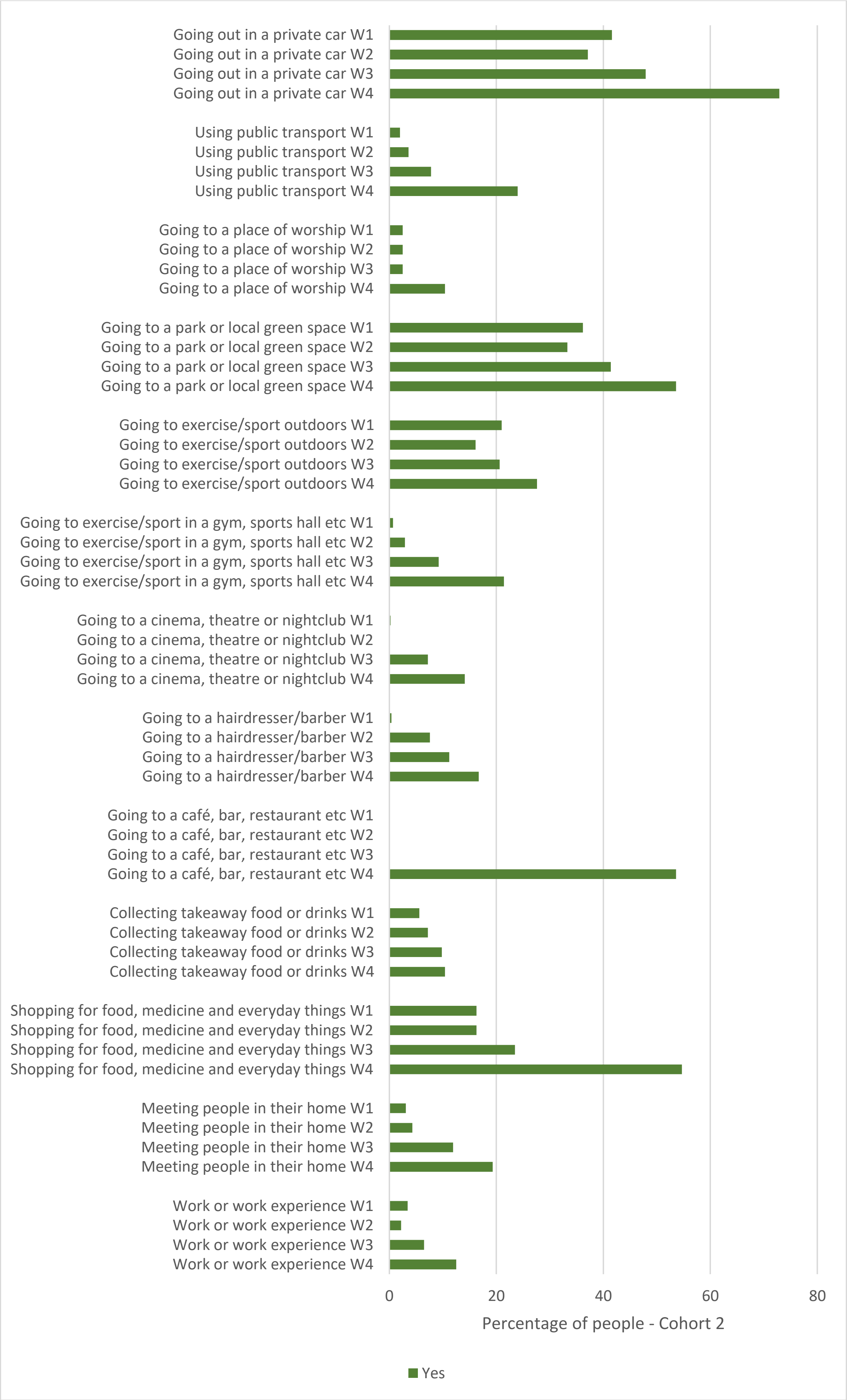
Going out in a private car W1
Going out in a private car W2
Going out in a private car W3
Going out in a private car W4
Using public transport W1
Using public transport W2
Using public transport W3
Using public transport W4
Going to a place of worship W1
Going to a place of worship W2
Going to a place of worship W3
Going to a place of worship W4
Going to a park or local green space W1
Going to a park or local green space W2
Going to a park or local green space W3
Going to a park or local green space W4
Going to exercise/sport outdoors W1
Going to exercise/sport outdoors W2
Going to exercise/sport outdoors W3
Going to exercise/sport outdoors W4
Going to exercise/sport in a gym, sports hall etc W1
Going to exercise/sport in a gym, sports hall etc W2
Going to exercise/sport in a gym, sports hall etc W3
Going to exercise/sport in a gym, sports hall etc W4
Going to a cinema, theatre or nightclub W1
Going to a cinema, theatre or nightclub W2
Going to a cinema, theatre or nightclub W3
Going to a cinema, theatre or nightclub W4
Going to a hairdresser/barber W1
Going to a hairdresser/barber W2
Going to a hairdresser/barber W3
Going to a hairdresser/barber W4
Going to a café, bar, restaurant etc W1
Going to a café, bar, restaurant etc W2
Going to a café, bar, restaurant etc W3
Going to a café, bar, restaurant etc W4
Collecting takeaway food or drinks W1
Collecting takeaway food or drinks W2
Collecting takeaway food or drinks W3
Collecting takeaway food or drinks W4
Shopping for food, medicine and everyday things W1
Shopping for food, medicine and everyday things W2
Shopping for food, medicine and everyday things W3
Shopping for food, medicine and everyday things W4
Meeting people in their home W1
Meeting people in their home W2
Meeting people in their home W3
Meeting people in their home W4
Work or work experience W1
Work or work experience W2
Work or work experience W3
Work or work experience W4
0
20
40
60
80
Percentage of people - Cohort 2
🟩 Yes

Figure 2.26. Reasons that people with learning disabilities left their house in the last week – Cohort 2 – Waves 1, 2, 3 and 4

By Wave 4, more than half of people in Cohort 1 had been leaving the house for everyday shopping (84% of people), going to exercise/sport such as walking, running or cycling outdoors (69%), going to a café, restaurant or bar (65%), travelling in a private car (64%), using public transport (56%), going to a park or local green space (54%), or going to work or work experience (52%). While the proportion of people in Cohort 1 going out for most reasons was similar from Wave 3 to Wave 4, there were increases from Wave 3 to Wave 4 in the proportion of people in Wave 4 going to a place of worship, going to do exercise/sport in a gym, sports hall or leisure centre, and going to work or work experience.

Generally, at Wave 4 fewer people in Cohort 2 were reported to be leaving the house for almost all reasons compared to people in Cohort 1, the one exception being going out in a private car (73% Cohort 2 vs 64% Cohort 1). The only reasons that more than half of people in Cohort 2 had left their house in the last week were travelling in a private car (73% of people), everyday shopping (55%), going to a park or green space (54%), and going to a café, restaurant, or bar (54%). In contrast to Cohort 1, the proportion of people in Cohort 2 going out for almost all the reasons we asked about increased substantially from Wave 3 to Wave 4.

In Wave 4, we also asked both cohorts some additional questions about how people got around, and what support people needed to go out.

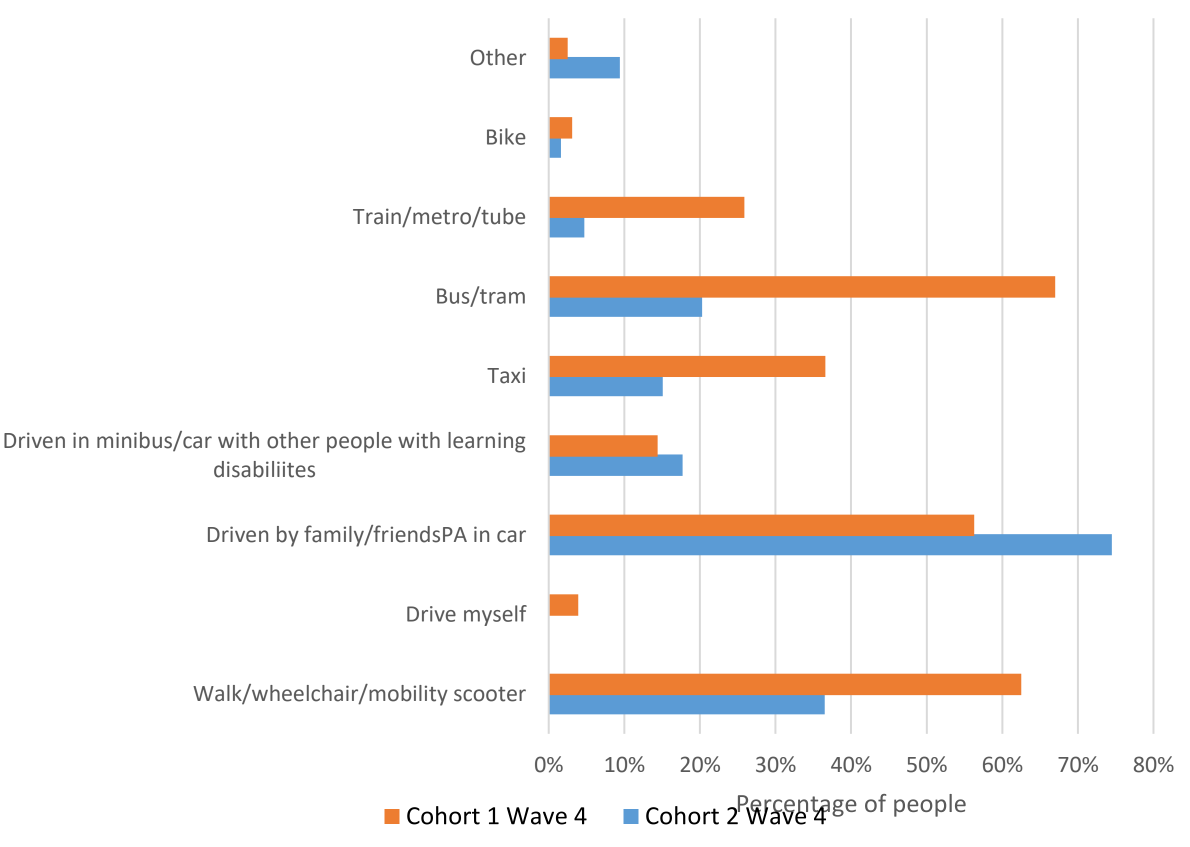

Figure 2.27. Ways that people usually get to places – Cohort 1 and Cohort 2, Wave 4

Figure 2.27 shows that at Wave 4 in Cohort 1 more than half of people usually got to places by bus/tram (67%), walking/wheelchair/mobility scooter (63%), or being driven by family/friends/PA in a car (56%). In Cohort 2 at Wave 4, by far the most common way of usually getting to places was being driven by family/friends/PA in a car (75%), with no other way used by more than half of people in Cohort 2. With the exception of being driven in a car and being driven in a minibus/car with other people with learning disabilities, people in Cohort 1 were more likely than people in Cohort 2 to use all other ways of getting to places.

At Wave 4, nearly half of people in Cohort 1 felt safe using public transport (48%), with a further 21% reporting feeling safe only if there was someone with them and a further 10% reporting only feeling safe in the daytime. In Cohort 1, 15% of people said they never used public transport. For Cohort 2, 4% of people were reported to feel safe on public transport, with a further 38% reported to feel safe only if someone was with them and a further 7% reported to only feel safe in the daytime. In Cohort 2, 11% of people were reported to never use public transport.

When asked if people usually needed someone to go with them when they wanted to go somewhere, over a third of people in Cohort 1 (38%) and the majority of people in Cohort 2 (89%) were reported to need someone with them. Over a third of people in Cohort 1 (38%) and a very small proportion of people in Cohort 2 (1%) did not need someone with them, and for 24% of people in Cohort 1 and 10% of people in Cohort 2 it depended on where they were going.

For those who needed someone to go with them when they wanted to go somewhere (at least some of the time), almost three quarters of people in Cohort 1 (73%) had someone usually around to help, compared to less than half of people in Cohort 2 (45%). For more people in Cohort 2, outings needed to be planned in advance (31%) compared to people in Cohort 1 (10%).

We asked people in both cohorts if anything gets in the way of them (Cohort 1), or the person they support (Cohort 2) going out when they want to go somewhere. For Cohort 1, most people responded that nothing got in the way of them going out when they wanted to go somewhere. However, the selected quotes in Box 2.1 illustrate a range of challenges faced by many participants. Commonly mentioned challenges included both physical and mental health; bad weather; the availability of family members or paid support workers as companions; the expense of going out; concerns about going out at night or somewhere unfamiliar; and availability of appropriate transport options. The selected quotes in Box 2.2 illustrate that for Cohort 2, there was a lack of availability of paid staff (in particular a lack of drivers) as well as barriers to going out caused by other commitments of family carers, and barriers associated with specific disabilities.

Box 2.1. Does anything get in the way of you going out when you want to go somewhere? (Cohort 1 only)

“Social anxiety when meeting new people”

"I have to wait until people are free to be able to go with me"

"Not usually, just sometimes my health gets in the way"

"The weather - thunderstorms, I hate it"

"I don't go out when it's snowing or icy on the floor, because of my disability my mobility is not so good"

“Sometimes short of staff cos if staff are ill, they can’t or they have a medical reason themselves so they can’t go out and we do something at home instead”

“Bank balance! Money. Is there a place that is going to be busier than normal that I should avoid - a mixture of covid and social anxiety”

"Just my confidence, sometimes I don't feel that confident"

"Hold ups if mum is busy"

"If the buses don't turn up it can be annoying, and on a Sunday not many buses run"

"Sometimes when you are trying to get on the bus, there is only one wheelchair space and it is taken, so then I can't get on the bus. It is also impossible to book a wheelchair accessible taxi when it is busy, so I can't always get to my self-advocacy group"

Box 2.2. Does anything get in the way of you going out when you want to go somewhere? (Cohort 2 only)

"One of his carers don't drive so they have to use the bus which means he can only go to certain places"

"There is always shortage of staff. And as my son is in supported living accommodation with another 5 people obviously the staff have to look after everybody and there are long waiting time for anything (going out, having breakfast, going to the bathroom, having a shower, etc)"

"Yes, sensory impairment"

"Shortage of support staff. Agency staff don't know clients well enough to take them out"

"My daughter needs 2 people to take her out. We plan to cover this with family members and PAs. Occasionally we don't have a second person and we have to stay at home"

"They have lost their confidence in going to places since the start of the pandemic. They are overly anxious"

"Everything has to be planned at least a month in advance, no spontaneity"

"Need to have a changing places facility as son is incontinent"

"The person can suffer with episodes of mental health decline, this can impact on where they want to go"

"I need to be available and well enough to take her. I have other caring responsibilities and am unwell, so when she wants to go, and what she wants to do is very restricted"

2.7.2. Local neighbourhoods

We asked participants about their local neighbourhoods, including about how safe they feel going out (Cohort 1 only), and whether people liked living in their neighbourhood. These data are presented in Figures 2.28.

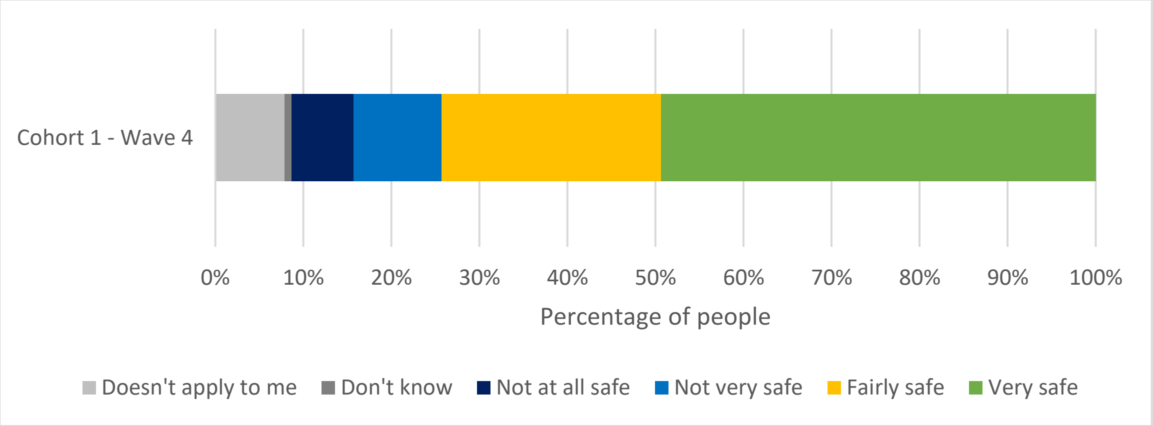

Figure 2.28. Thinking about where you live, how safe would you feel walking on your own during the day in a quiet street close to your home? (Cohort 1 only) Wave 4

People with learning disabilities in Cohort 1 most commonly reported that they felt very safe when walking alone during the day in a quiet street close to their home (47%), with 18% of people feeling not at all safe or not very safe.

The vast majority of people in Cohort 1 (91%) reported that they liked living in their neighbourhood. The figures for people in Cohort 2 were reported by family carers or support workers to be similar (83%), with more don't knows among Cohort 2 (15%) than Cohort 1 (2%) respondents.

2.7.3. Paid employment and voluntary work

In Cohort 1 at Wave 4, 126 people with learning disabilities (36%) reported that they had a paid job at the moment (see Table 2.12), almost two thirds of which (63%) were for fewer than 16 hours per week. Almost everyone in Cohort 1 with a paid job said they liked their job (94%). While most people in Cohort 1 with a paid job were not working from home (59%), almost a third had hybrid jobs (31%) and a minority (10%) were working completely from home.

In Cohort 2, nine respondents (5%) reported that the person they support/care for had a paid job at the moment, with almost all these jobs being for fewer than 16 hours a week.

For people in Cohort 1, by Wave 4 paid employment levels had returned to pre-COVID-19-pandemic levels (32% of people in Cohort 1 at Wave 1 reported having a paid job before the pandemic, with paid employment rates lower at Wave 1 then increasing over time). Paid employment rates were much lower among people in Cohort 2, but followed the same pattern over time (at Wave 1, 5% of people in Cohort 2 were reported to have had a paid job before the COVID-19 pandemic).

In terms of voluntary work (see Table 2.12), 43% of people in Cohort 1 at Wave 4 reported doing voluntary work, mostly at least once a week. This compares to 50% of people in Cohort 1 at Wave 1 reporting doing voluntary work before the COVID-19 pandemic, with levels of voluntary work lower at Wave 1 (15%) then increasing over time.

At Wave 4, 11% of people in Cohort 2 were reported to be doing voluntary work, mostly at least once a week, compared to 16% of people in Cohort 2 who were reported at Wave 1 to have been doing voluntary work before the COVID-19 pandemic.

Table 2.12. Paid employment and voluntary work – Wave 4

	Cohort 1	Cohort 2
Paid job at the moment		
Yes, full-time	5%	0%
Yes, part-time	31%	5%
No	65%	95%
Hours paid work (of those with a paid job)		
16+ hours a week	36%	11%
Less than 16 hours a week	63%	89%
Don't know	2%	0%
Voluntary work		
Yes, regular (at least once a week)	33%	8%
Yes, occasional (less than once a week)	10%	3%
No	56%	89%

2.7.4. Money

At all four waves, we asked family members or support workers of people in Cohort 2 if the person with learning disabilities they were caring for/supporting had enough money at the moment. We also asked this question to people in Cohort 1 at Wave 4. The results are presented in Figure 2.29 below.

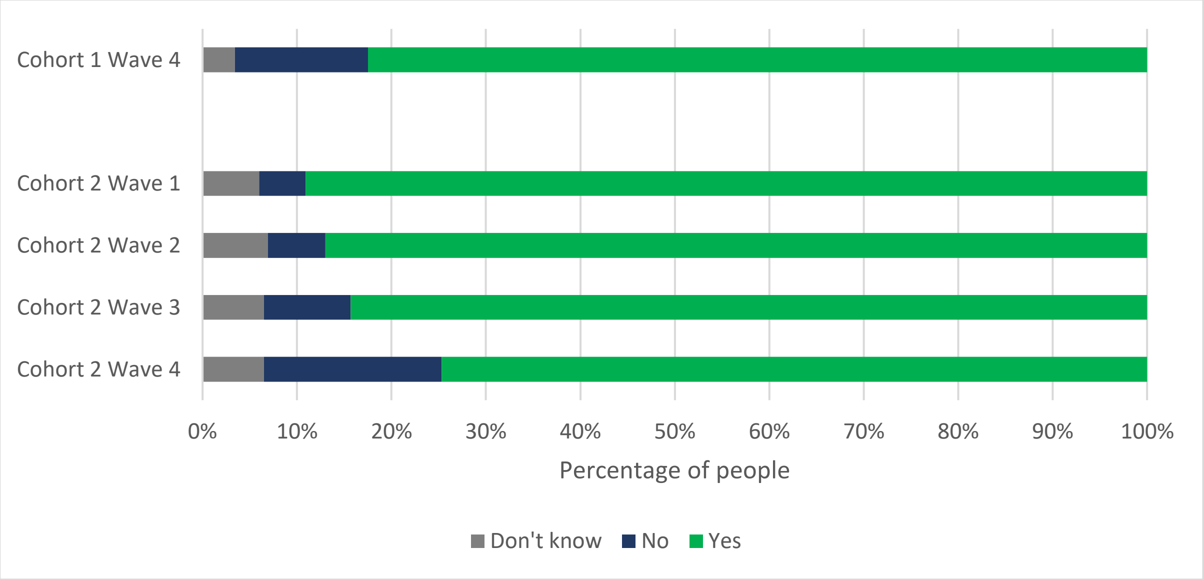

Figure 2.29. Does the person you support/care for have enough money at the moment? (Wave 4 Cohort 1; Waves 1, 2, 3, 4 Cohort 2)

For Cohort 1 at Wave 4, one in seven people (14%) said that they did not have enough money at the moment, with a substantial majority (83%) saying that they did enough money. For Cohort 2 the number of people reported not to have enough money at the moment increased gradually from Wave 1 (5%) to Wave 3 (9%), with a bigger increase to Wave 4 (19%) where almost one in five people were reported not to have enough money at the moment. By Wave 4, three quarters of people in Cohort 2 (75%) were reported to have enough money at the moment, down from 89% of people in Cohort 2 at Wave 1.

At Wave 4, we also asked Cohort 1 and Cohort 2 if in the last four weeks there had been enough household money for a range of things when the person with learning disabilities wanted them, ranging from energy for heating and lighting through to holidays. Figures 2.30 (Cohort 1) and 2.31 (Cohort 2) present this information.

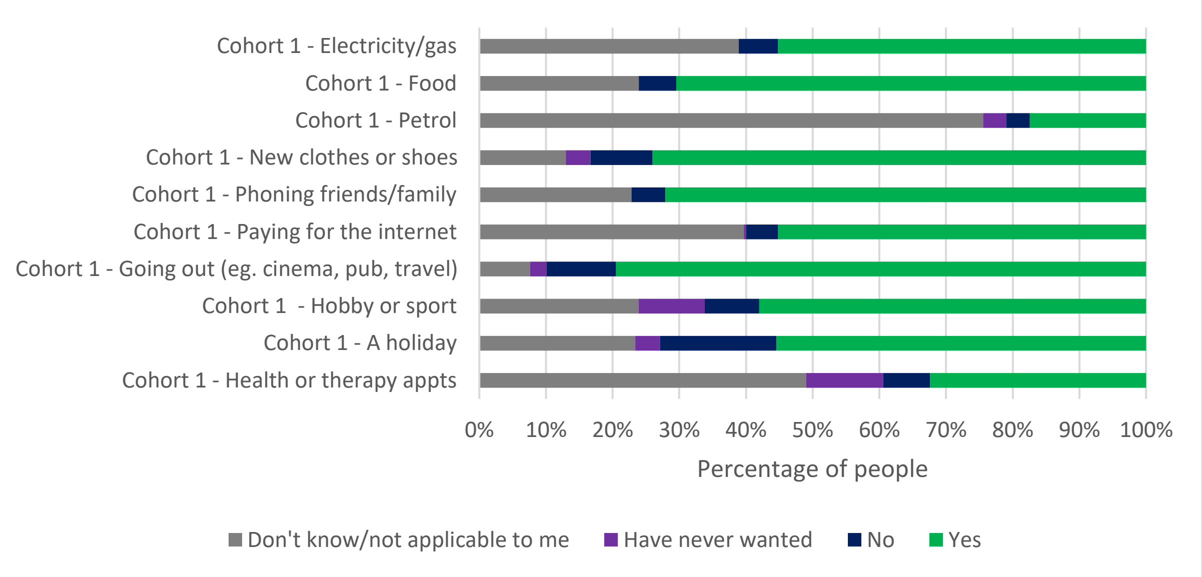

Figure 2.30. Has there been enough money in the household in the last four weeks for these things when the person with learning disabilities wants them? (Cohort 1 Wave 4)

For Cohort 1, it is important to note that large proportions of people reported that they did not know about money for a wide range of things or that the question was not applicable to them, indicating that others are often in charge of paying for energy, petrol, internet etc and that many people with learning disabilities do not have control over money. People in Cohort 1 most commonly said that they did not have enough money for a holiday (18% of people in Cohort 1), going out (10%), new clothes or shoes (9%), or a hobby/sport (9%), suggesting cost of living restrictions affecting active social and leisure lives.

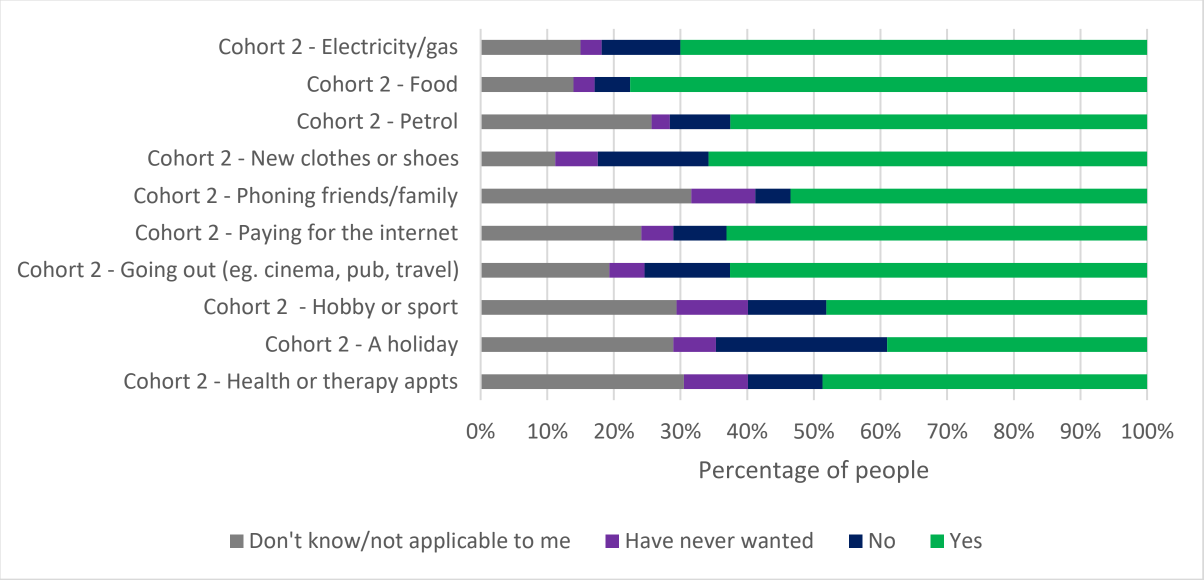

Figure 2.31. Has there been enough money in the household in the last four weeks for these things when the person with learning disabilities wants them? (Cohort 2 Wave 4)

For Cohort 2, relatively large proportions of family carers or support workers also reported that they did not know about money for a wide range of things or that the question was not applicable to the person they were caring for/supporting, possibly because Cohort 2 respondents were not always living in the same place as the person with learning disabilities or respondents would not always know the details of the financial situation for people. People in Cohort 2 most commonly said that the person they were caring for/supporting did not have enough money for a holiday (26% of people in Cohort 2), new clothes or shoes (17%), going out (13%), a hobby/sport (12%), electricity/gas (12%) and health or therapy appointments (11%), suggesting pervasive cost of living restrictions on the lives of some people with learning disabilities in Cohort 2.

2.8. What is difficult and what is going well?

What is difficult? People in both cohorts were asked an open-ended question about one thing that is most difficult about their life (Cohort 1) or about the life of the person being supported (Cohort 2) at the moment.

For Cohort 1, most people said nothing was difficult. However, many people found a range of different aspects of their life difficult at the time of their Wave 4 interview. Difficulties included relationships with partners, family and/or friends; physical and mental health; financial concerns and the cost-of-living crisis; ongoing issues with COVID-19 closures; loneliness; and a lack of things to do.

For Cohort 2, responses included reference to specific health issues affecting quality of life; communication challenges; services not having returned to pre-pandemic levels; mental health concerns; lack of activities; isolation and boredom; difficultly accessing health services; lack of respite care; and social care staff shortages. Selected quotes to illustrate these difficulties are included in Boxes 2.3 and 2.4 below.

Box 2.3. What is one thing you would say is most difficult in your life at the moment? (Cohort 1 only)

"When I have no money I get upset a bit"

"Finding activities to do because I am lonely and I never go anywhere"

"Well, I would like doctors and all that to come back to face to face full time. I would like things back face to face"

"It makes me sad when I think of my aunt and uncle who died"

“Anxiety. I always feel like I’m on edge. Covid, cost of living crisis, finances, current living arrangement. The majority don’t seem to care about covid anymore and you can’t just ignore it, people are still dying from it”

"Doing activities because it is hard to get there and because of restrictions that are still in place due to Covid"

"Being with my girlfriend as she as quite difficult"

"My friends can sometimes be hard work!"

"Evenings when there is no social club on or if I want to go for a walk there is no one to go out with me"

"Cost of living feels like another lock-down"

"Trying to see my GP. Don't want to do it over the phone"

"I’m having some difficulty with my neighbour at the moment"

"Waiting on hospital appointments. Makes me feel fed up"

"Keeping safe from Coronavirus"

"I miss my art project. The council withdrew funding"

"Some shops I used to go to have closed down. I have to travel farther now for some things I want"

"Staff hours have been cut - they only work till 5.30pm now and they used to work until 8pm so I have to get used to that"

Box 2.4 What is one thing you would say is most difficult in your life at the moment? (Cohort 2 only)

"As yet they have not returned to normal activities that they had before COVID"

"Poor quality support, by poorly trained and staff with turnover of managers"

"Not seeing her friends as often"

"Lack of opportunity for social interaction in small, supportive groups. Lack of support staff. Lack of choice about life and lifestyle - ie housing"

"Uncertainty about future services in our current climate"

"Having complex health condition that means keeping away from people who may give him Covid. He could die if he caught it"

"Lack of physical, stimulating activities. Too much time spent indoors doing the same 3 things day in day out. Boredom/agitation shows in picking at skin. Life"

"Communication. As always, being non-verbal means that my daughter has great difficulty making her feelings and needs known"

"Reduced stability in staff team. Not always staff who know then well"

"Still not gone back to clubs that were running pre-covid. Hydrotherapy & rebound were a wonderful way to get movement and exercise done, sadly, sitting in wheelchair/comfy chair at home all day"

"Lack of things to do and places to go. Lack of social work involvement or services"

"Isolation. He does not leave the house. No support or help from outside agencies. Not able to see a GP. Worrying about money. Worrying about fuel bills. Unable to get any help"

"Anxiety about change. Pandemic definitely made her unsure of things and worried about whether her life is going to be changed suddenly"

"Lack of residential respite care. Used to be 10 weeks a year. Now only in emergencies on ad hoc basis"

What is going well? People in both cohorts were asked an open-ended question about one thing that is going well in their (Cohort 1) or the person being supported's (Cohort 2) life at the moment (see Boxes 2.5 and 2.6). For Cohort 1, there were many responses relating to seeing friends and family. Some responses were linked to the easing of COVID-19 health protection measures as well as responses referring to a range of different aspects of people's lives such as paid and volunteering work; improved health; independence; making plans (e.g., holidays); hobbies and activities. Many of the responses from people in Cohort 2 were around relationships with family, friends, and paid support workers. Some responses made specific reference to life returning to how it was pre-pandemic.

Box 2.5. What is one thing you would say is going well in your life at the moment? (Cohort 1 only)

"Having a job, I work a care home for people with dementia, I work in the kitchen and with the people, I really love my job"

“Going on holiday soon, getting away from everywhere and meeting other people”

"Having two new jobs and doing more things online on zoom particularly work. I am so much happier and I've got life on track"

“Now we can go out places, things like that, that’s going well!”

"Being in touch with family and friends and getting to go out"

"I don't know. I suppose I am managing to live independently. Lots of people didn't think I would manage it, but I think I am doing pretty well"

"My friends and family being around me at the moment"

"Everything being back to normal makes me happy"

"I am enjoying cooking and my job"

“My health is getting better”

"Being out and about more"

Box 2.6. What is one thing you would say is going well in your life at the moment? (Cohort 2 only)

"The calibre of the team of PAs is magnificent"

"She sees life getting back to a bit of normality before Covid"

"Life has returned to normal in terms of activities etc"

"In his own home - his care team really like him and he them and he is loving life as everything happens on his timetable"

"Being able to video call friends - a skill learned through lockdown"

"He feels secure and loved with family"

"He has something to do every day and seems quite happy"

"Going to day service and meeting with friends every day"

"He does get on with support workers and enjoys trips out"

"His day care is very oriented to singing and dancing and he loves it"

"Love and support provided by family"

"Very much enjoying her college art course"

2.9. Future considerations

In both cohorts, we asked about how long people thought it would be until their lives went back to normal.

Figures 2.32 and 2.33 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, as reported at Wave 4.

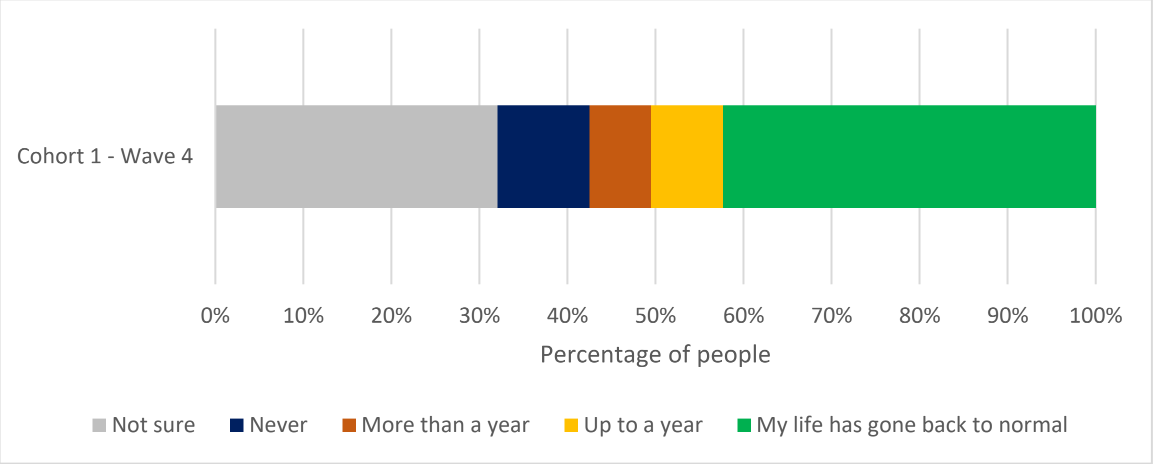

Figure 2.32. How long do you think it will be before your life goes back to how it was before the COVID-19 pandemic? Cohort 1 Wave 4

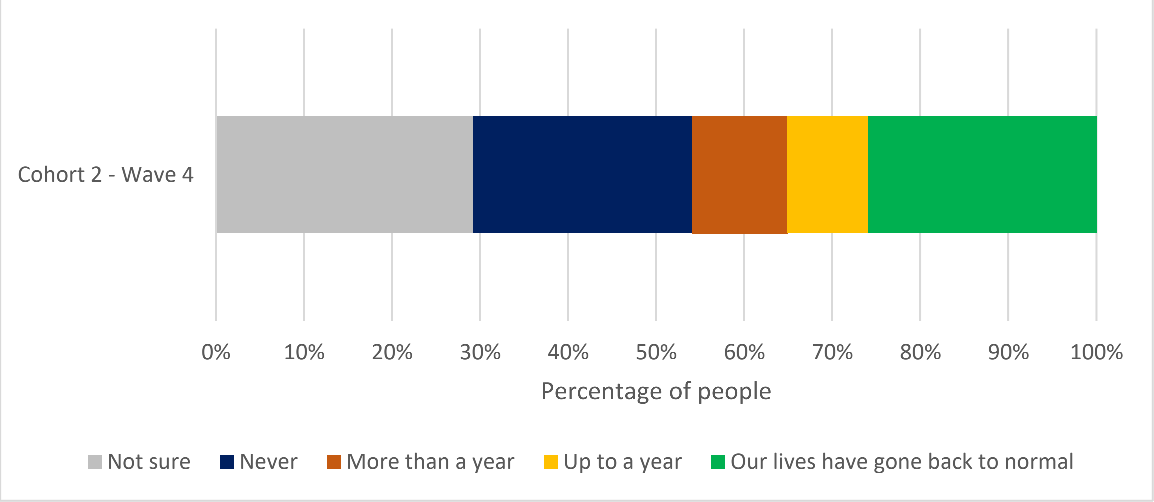

Figure 2.33 How long do you think it will be before your life/the life of the person you support/care for returns to how it was before the COVID-19 pandemic? Cohort 2 Wave 4

In Cohort 1, over two fifths of people (42%) said at Wave 4 that their lives had returned to normal, a large increase from Wave 3 (5% of people in Cohort 1). However, at Wave 4 almost a third of people in Cohort 1 (32%) were not sure when their lives would return to normal (compared to 35% at Wave 3), and 10% of people said their lives would never return to normal (compared to 9% of people at Wave 3).

In Cohort 2, a quarter of family carers and support workers at Wave 4 (26%) said that the lives of the people they cared for/supported had returned to normal, again a large increase from Wave 3 (3%). However, a further quarter of people in Cohort 2 at Wave 4 (25%) said that the person's life would never return to normal, also an increase from Wave 3 (13%). The most common response to this question in Cohort 2 at Wave 4 (29%) was that people were not sure when life would return to normal, a similar proportion to that reported at Wave 3 (26%).

The most recent available information using this question for adults in Great Britain was for February 2022, which reported that 16% of disabled adults and 10% of non-disabled adults thought that their life would never return to normal[10].

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[10] Office for National Statistics, 16 March 2022. Coronavirus (COVID-19): disabled people are more likely to feel life will never return to normal. https://www.ons.gov.uk/peoplepopulationandcommunity/wellbeing/articles/coronaviruscovid19disabledpeoplearemorelikelytofeellifewillneverreturntonormal/2022-03-16

Chapter 3: The health and wellbeing of family carers: Results from Cohort 2 participants

3.1. Health and wellbeing

We asked about the health and wellbeing of family carers across all four waves of the project. First, we asked family carers how happy they were feeling the day before completing the survey (0-10 scale where 10 is the happiest) and how anxious they were feeling the day before completing the survey (0-10 scale where 10 is the most anxious). Mean scores at each wave are presented in Figure 3.1 below

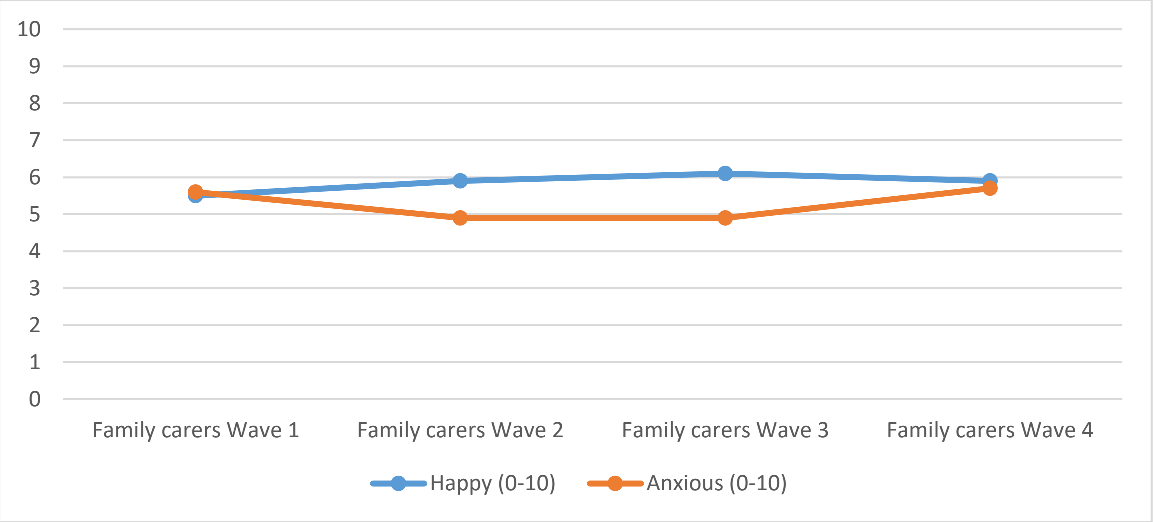

Figure 3.1: Mean happiness and anxiety scores for family carers – Waves 1, 2, 3 and 4

Family carer mean scores on happiness and anxiety were fairly consistent across all four waves.

At Wave 4, the mean happiness score for family carers (5.9) was approximately 1 point lower than the mean happiness score for adults in Great Britain (6.8-7.0) reported for the same time period by the ONS[11]. At Wave 4, the mean anxiety score for family carers (5.7) was approximately 1.5 points higher than the mean anxiety score for adults in Great Britain (4.0-4.2) reported for the same time period by the ONS.

We also asked family carers about their self-reported health in general at the moment, again across all four waves, reported in Figure 3.2 below.

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[11] Office for National Statistics, 13 Dec 2022. Public opinions and social trends, Great Britain: 7 to 18 December 2022. Access to personal well-being dataset. https://www.ons.gov.uk/peoplepopulationandcommunity/wellbeing/bulletins/publicopinionsandsocialtrendsgreatbritain/7to18december2022

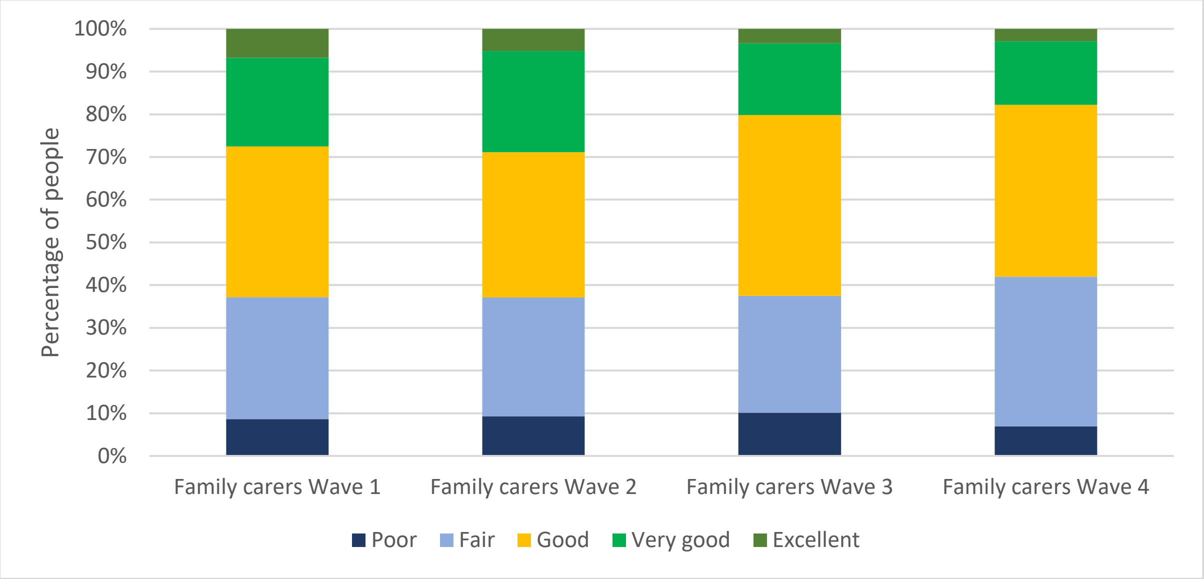

Figure 3.2: How is your health in general? Family carers, Waves 1, 2, 3 and 4

The self-reported general health of family carers continued to worsen from Wave 1 to Wave 4. By Wave 4, 18% of family carers rated their health as excellent or very good, compared to 28% of family carers at Wave 1 (during a national lockdown). Also at Wave 4, 45% of family carers at Wave 4 rated their health as fair or poor, compared to 37% of family carers at Wave 1.

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

At Wave 4, the most common health impacts of the caring role experienced by over half of family carers in the last four weeks continued to be feeling tired (73% of family carers), a general feeling of stress (65%), and disturbed sleep (56%). Health impacts experienced by over a quarter of family carers at Wave 4 were feeling depressed (40% of family carers), feeling short-tempered/irritable (36%) and physical strain (32%). Fewer than one in ten of family carers at Wave 4 (8%) said that they had not experienced any of these health impacts as a result of their caring role in the last four weeks.

In terms of trends over time, the prevalence of almost all health impacts were broadly consistent over time (feeling depressed, loss of appetite, disturbed sleep) or gradually increasing over time (feeling tired, general feeling of stress, physical strain, short-tempered/irritable, developed own health needs, made an existing condition worse). Despite more family carers at Wave 4 reporting developing or worsening health conditions as a result of caring, fewer family carers at Wave 4 than at earlier waves reported having to contact their own GP (11% Wave 1; 16% Wave 2; 14% Wave 3; 10% Wave 4).

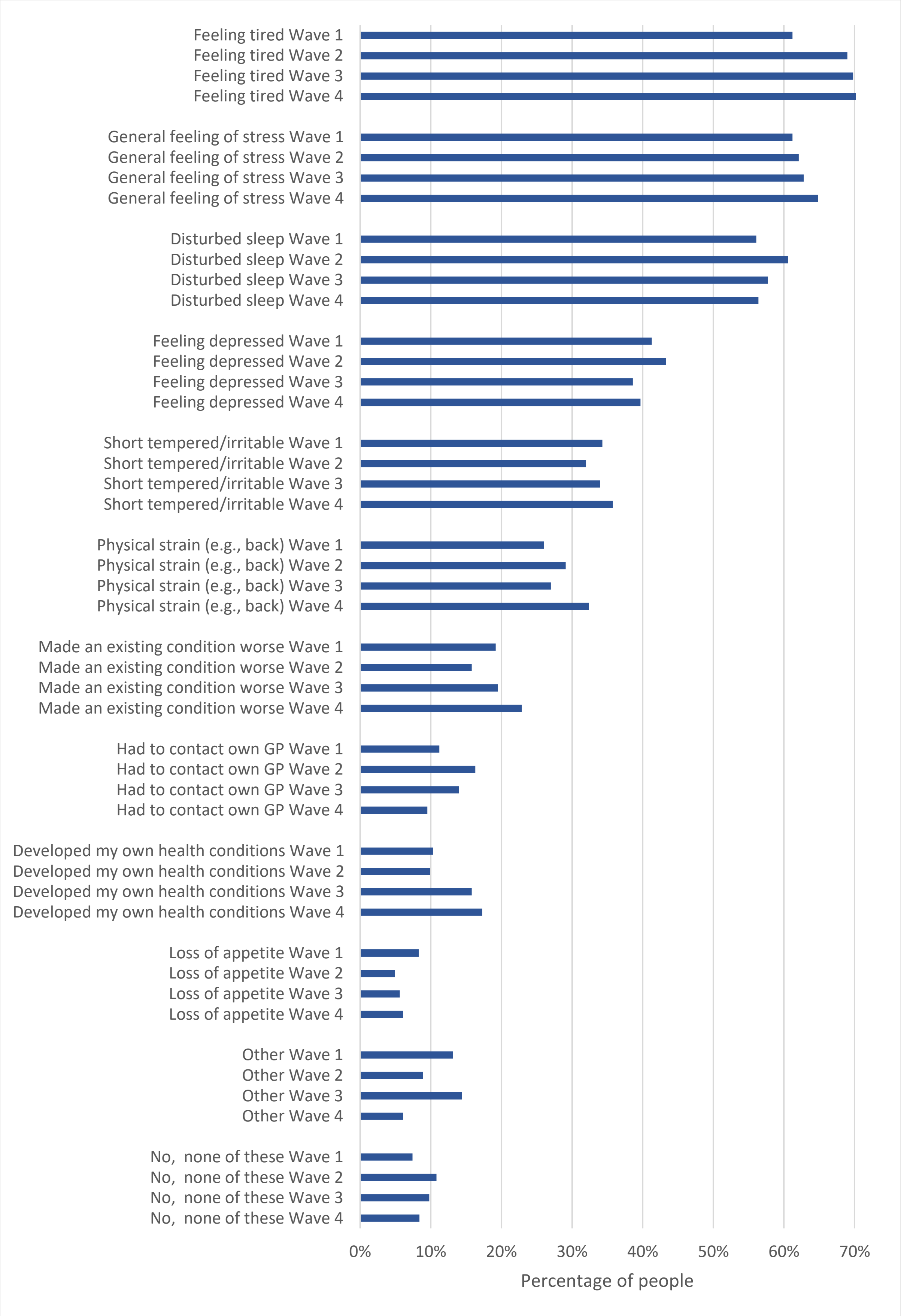

Figure 3.3. In the last four weeks, has your health been affected by your caring role in any of these ways? (Select all that apply) Family carers, Waves 1, 2, 3 and 4

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 at Wave 4.

4.1. Descriptive data about people with PMLD

In Cohort 2, at Wave 4 44% of participants were supporting/caring for people with PMLD, 47% were supporting/caring for someone without PMLD, and 3% did not know if PMLD applied to the person they were supporting/caring or not. For analyses in this chapter, comparisons are made between those in Cohort 2 with PMLD and all other people in Cohort 2 (combining the not PMLD and don't know responses).

At Wave 4, people with PMLD were living in: Scotland (45% of people with PMLD), England (28%), Wales (16%) and Northern Ireland (11%). Other people in Cohort 2 were living in: England (53%), Wales (21%), Scotland (16%) and Northern Ireland (10%).

At Wave 4, people with and without PMLD were similar ages (mean 33 years (17-66 years) people with PMLD; mean 33 years (16-73 years) people without PMLD). In both groups, just over half of people were men (people with PMLD 56% men; people without PMLD 55% men), with the vast majority of people being White British (87% people with PMLD; 92% people without PMLD). In Cohort 2, fewer people with PMLD had Down syndrome (15%) that people without PMLD (27%). Similar proportions of people with and without PMLD had a professional diagnosis of autism (48% people with PMLD vs 48% people without PMLD) or in the absence of a diagnosis were identified as autistic by the family carer/support worker (13% people with PMLD; 10% people without PMLD).

Detail about who people with and without PMLD in Cohort 2 lived with at Wave 4 is presented in Table 4.1 below. At Wave 4, 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 (37%). 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 (43%) than getting this type of support (12%). Substantial numbers of people with and without PMLD in Cohort 2 lived alone or with others in some form of supported accommodation/supported living (23% and 25% respectively), with fewer people living in residential care (8% and 12% respectively).

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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

Table 4.1. Wave 4 Cohort 2: Who people with and without PMLD live with

Cohort 2	People with PMLD	People without PMLD
Live alone with support in supported living/rented/owned accommodation	11%	9%
Live with other people with support in supported living/rented/owned accommodation	12%	16%
Live with other people with support in residential care	8%	12%
Live with family without paid support workers coming into the family home	37%	43%
Live with family with paid support workers coming into the family home	29%	12%
Live in a Shared Lives arrangement	1%	5%
Live in a different type of place (including secure placements)	2%	3%

4.2. COVID-19

Having COVID-19. By Wave 4, more than two thirds of people with PMLD were reported to have had COVID-19 (71%), compared to less than two thirds of people in Cohort 2 without PMLD (63%). At Wave 4, of those reported to have had COVID-19, most people with PMLD (82%) and people in Cohort 2 without PMLD (84%) were reported to have had COVID-19 once.

At Wave 3, in July/August 2021 (after most public health protections had just ceased), 14% of people with PMLD and 14% of people without PMLD in Cohort 2 were reported to have had COVID-19.

COVID-19 vaccines. By Wave 4, almost three quarters of people with PMLD (74%) and the vast majority of people without PMLD in Cohort 2 (86%) had had 3 or 4 doses of the COVID-19 vaccine. More people with PMLD (8%) than people without PMLD in Cohort 2 had not had the COVID-19 vaccine. Similar proportions of family carers or support workers of people with (83%) and without (88%) PMLD in Cohort 2 Wave 4 said the person would have a booster COVID-19 vaccine in the winter if it was needed (at the time of the survey design, there had been no official announcement about a winter booster programme).

COVID-19 testing. At Wave 4, over a third of people with PMLD (36%) and over half of people without PMLD in Cohort 2 (52%) were reported to have had at least one COVID-19 test in the last four weeks. Both groups most commonly had had a test once or twice in the last four weeks (28% people with PMLD; 31% people without PMLD) rather than more frequently.

Keeping safe. In Cohort 2 at Wave 4, over a third of people with PMLD (35%) and people without PMLD (35%) were reported by family carers and support workers not to be doing anything specific to keep themselves safe from COVID-19 (see Figure 4.1 below). Among people with PMLD in Cohort 2, the most common ways of keeping safe were trying not to be in big groups of people (43% of people), staying at home more (29%) and washing hands more (26%). Among people without PMLD in Cohort 2, the most common ways of keeping safe were washing hands more (49%), wearing a face mask sometimes when out (32%) and trying not to be in big groups of people (30%).

By Wave 4, 3 people with PMLD (4% of people) and 1 person without PMLD in Cohort 2 (1%) were reported to be shielding. At Wave 3, in July/August 2021, 23% of people with PMLD and 17% of people without PMLD in Cohort 2 were reported to be shielding.

At Wave 4, over a quarter of family carers or support workers of people with PMLD (30%) and of people without PMLD in Cohort 2 (26%) reported still wearing some form of PPE when in close contact with the person they were caring for/supporting.

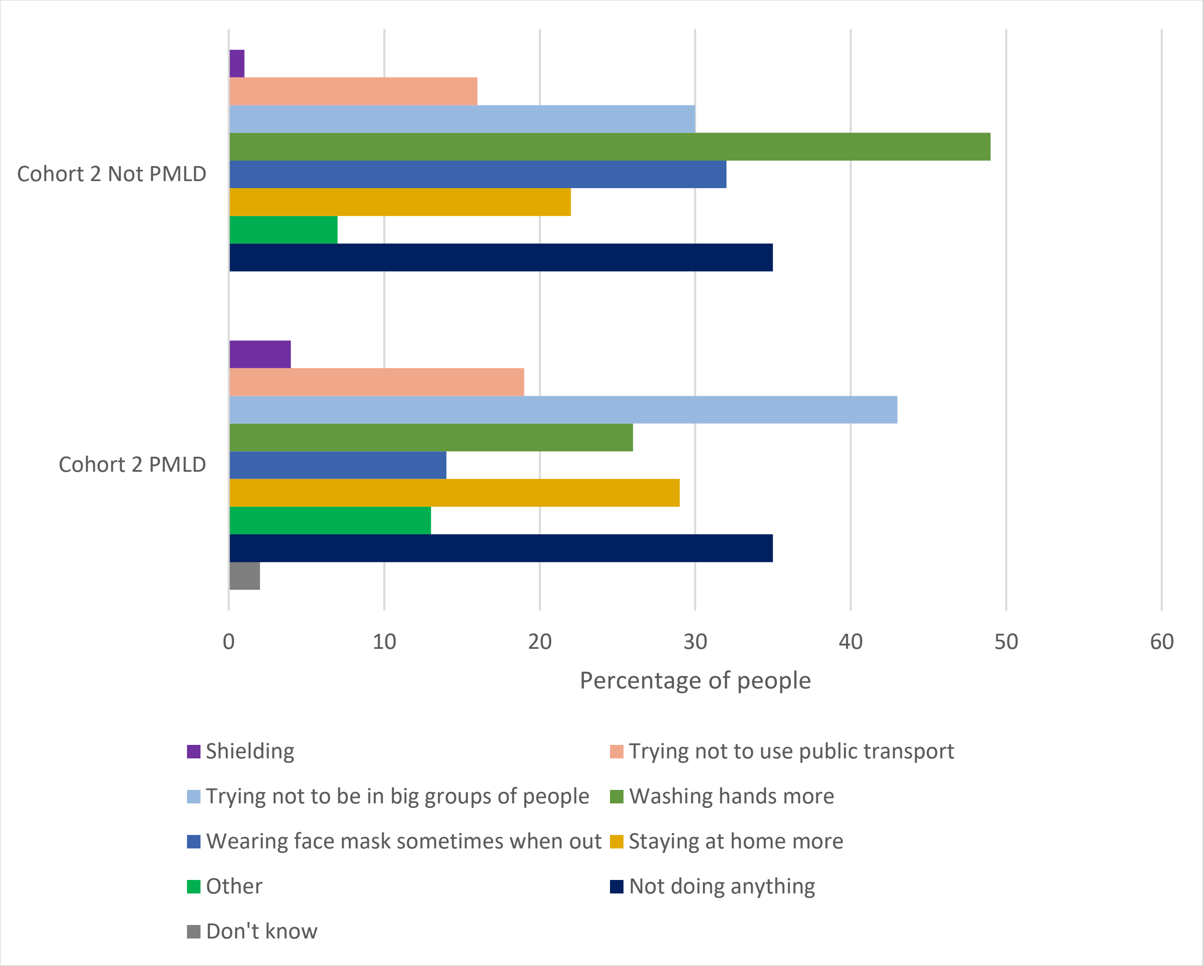

Figure 4.1. Wave 4 – what people are doing at the moment to keep themselves safe from COVID-19 (tick all that apply) – Cohort 2. People with PMLD vs people without PMLD

Information about COVID-19. We asked family carers or support workers about how they had found out anything they wanted to know about COVID-19 in the four weeks before the survey. The sources of information used by family carers/support workers of people with and without PMLD in Cohort 2 were broadly similar, for both groups most commonly government websites (24% PMLD group; 26% not PMLD group) and television news (29% PMLD group; 22% not PMLD group).

4.3 Physical health and access to health services

Section 2.3 earlier in this report discusses in detail the findings relating to physical health and access to a range of health services. In this section we focus on selected questions relating to physical health and access to health services of particular relevance to people with PMLD, or where there are clear differences between people with and without PMLD in Cohort 2 at Wave 4.

Contact with GPs In Waves 2, 3 and 4 we asked family carers/support workers (Cohort 2) whether the person with learning disabilities had been in contact with a GP in the last four weeks, and whether they had seen the GP in person (rather than by ‘phone or video link). In Wave 1 we had asked this question differently, in relation to GP contact since the start of the COVID-19 pandemic and regular contact before the pandemic.

Figure 4.2 below shows the percentage of people with PMLD and people without PMLD in Cohort 2 who had not seen their GP in the last four weeks, and the percentage of people who had seen their GP in person, across Waves 2, 3 and 4.

Fewer people with PMLD (57%) than people without PMLD in Cohort 2 (67%) had not seen their GP in the last four weeks at Wave 4, with more people with PMLD seeing their GP in person (16% people with PMLD vs 13% people without PMLD) or by ‘phone (14% people with PMLD vs 12% people without PMLD). The overall levels of people seeing a GP has stayed fairly consistent for both groups across Waves 2, 3 and 4, with increasing proportions of in-person contacts accompanied by decreasing ‘phone contacts.

At Wave 1, 42% of people with PMLD and 36% of people without PMLD in Cohort 2 were reported to have seen their GP regularly before the first COVID-19 lockdown.

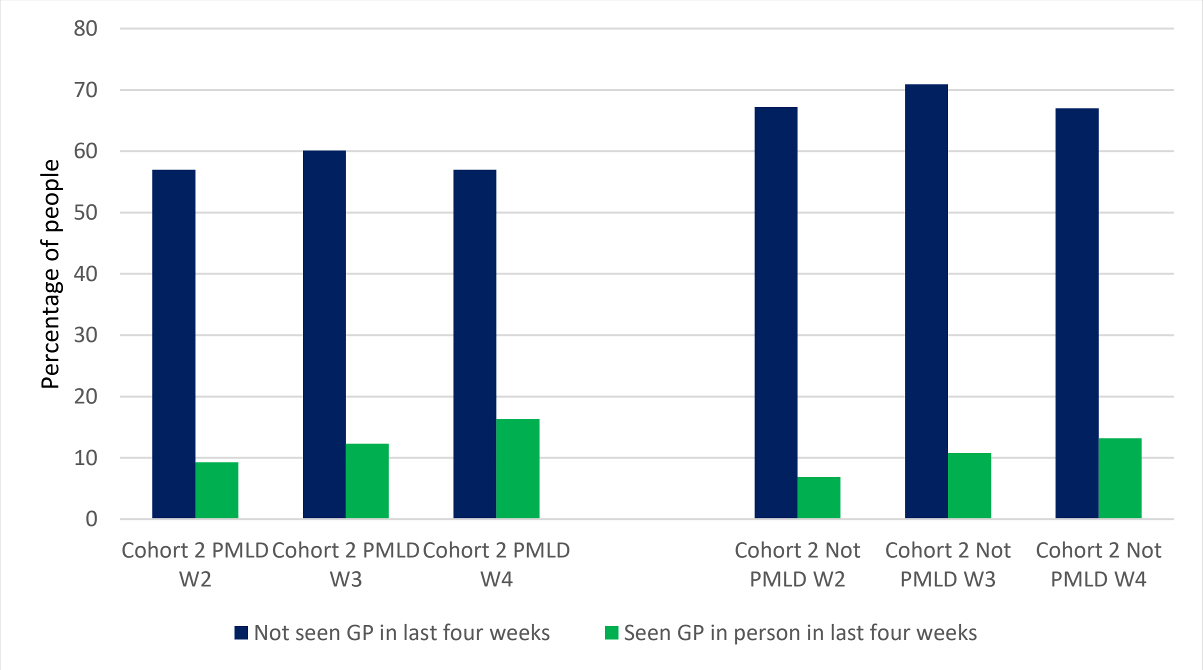

Figure 4.2. In the last four weeks have you/the person you support/care for been in contact with a GP? Wave 2, Wave 3, Wave 4. People with PMLD vs people without PMLD Cohort 2

Contact with other health professionals. Using the same format of questions we asked concerning contact with GPs in the last four weeks, at Waves 2, 3 and 4 we asked about contact with: community nurses; psychiatrists/clinical psychologists/counsellors; and other therapist (e.g. speech and language therapists; occupational therapists or physiotherapists).

Findings for community nurses at Wave 4 were similar for people with and without PMLD in Cohort 2: 80% of people with PMLD and 81% of people without PMLD in Cohort 2 had not seen a community nurse in the last four weeks, fewer people than at Waves 2 and 3. At Wave 1, 30% of people with PMLD and 23% of people without PMLD in Cohort 1 were reported to have seen a community nurse regularly before the COVID-19 pandemic.

Findings for psychiatrists/clinical psychologists/counsellors were also similar for people with PMLD and people without PMLD in Cohort 2 at Wave 4: 85% of people with PMLD and 88% of people without PMLD in Cohort 2 had not seen one of these mental health professionals in the last four weeks, which represented similar levels to Waves 2 and 3. At Wave 1, 19% of people with PMLD and 25% of people without PMLD in Cohort 1 were reported to have seen one of these mental health professionals regularly before the COVID-19 pandemic.

Figure 4.3 below presents the findings for contact with another type of therapist, such as a speech and language therapist, occupational therapist or physiotherapist. For people with PMLD at Wave 4, less than two thirds of people (64%) had not seen another type of therapist in the last four weeks, with a higher figure for people without PMLD in Cohort 2 (80%). The proportion of people with PMLD seeing another type of therapist increased over time, whereas it stayed consistent for people without PMLD in Cohort 2. In both groups, the proportion of people seeing another type of therapist in person increased over time, while ‘phone contacts decreased over time.

At Wave 1, 41% of people with PMLD and 23% of people without PMLD in Cohort 2 were reported to have regularly seen another type of therapist before the first COVID-19 lockdown.

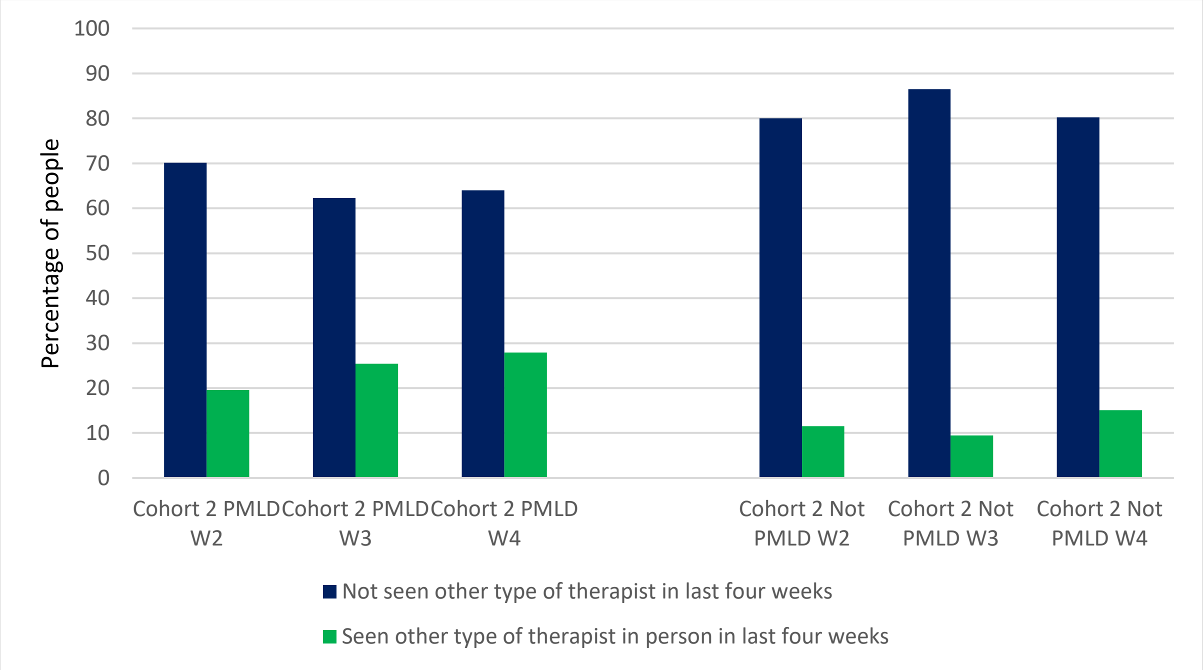

Figure 4.3. In the last four weeks have you/the person you support/care for been in contact with another type of therapist? Wave 2, Wave 3, Wave 4. People with PMLD vs people without PMLD in Cohort 2

Current physical health. Figure 4.4 shows how family carers and support workers of people with and without PMLD in Cohort 2 rated the health of the person they were caring for/supporting, across all four waves.

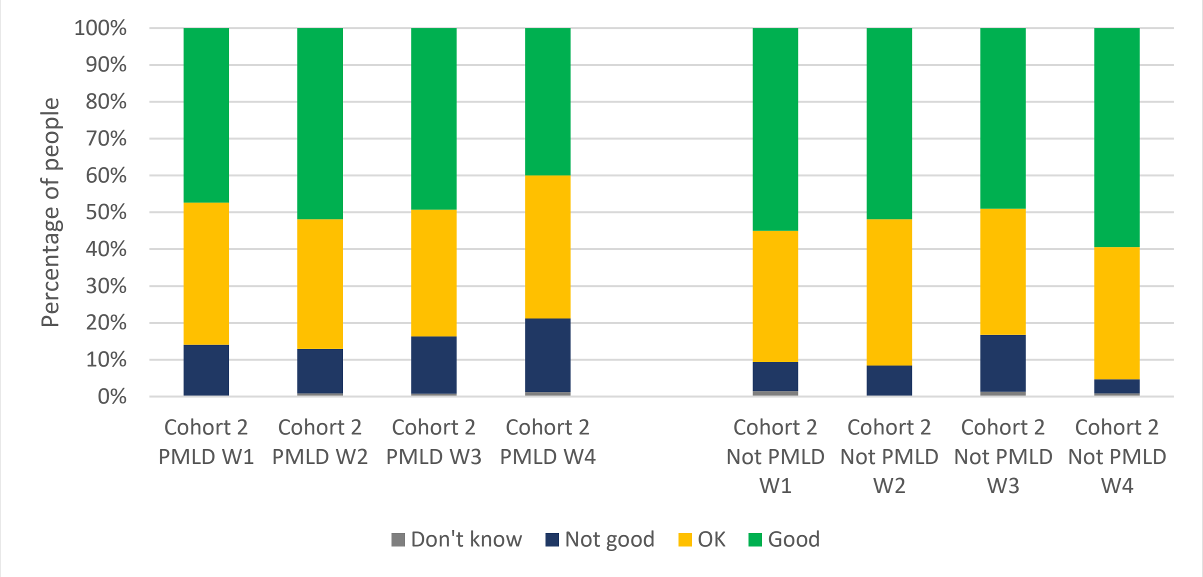

Figure 4.4: How is the health of the person you care for/support today? (Cohort 2) People with PMLD vs people without PMLD

The health of people with PMLD was reported to be worse at Wave 4 than at all earlier waves, with the health of 40% of people reported to be good and the health of 20% reported to be not good. The trajectory over time for people without PMLD in Cohort was different – by Wave 4 the health of 59% of people was reported to be good (the highest prevalence across all four waves) and the health of 4% of people was reported to be not good.

At Wave 4, over a third of people with PMLD (35%), compared to 18% of people without PMLD in Cohort 2, were reported to have had worsening or new (non-COVID) health conditions in the last four weeks.

Dentists, eye tests and hearing tests. At Wave 4, relatively few people with PMLD 5%) or without PMLD in Cohort 2 (11%) were reported to have had toothache in the last six months, with 61% of people with PMLD and 76% of people without PMLD in Cohort 2 reported to have been to the dentist in the last year.

In terms of eye tests, at Wave 4 less than a third of people with PMLD (31%) were reported to have had an eye test in the last year, with a further 9% of people last having an eye test in the last 1-2 years and almost half of people (47%) last having an eye test more than 2 years ago. People without PMLD in Wave 4 were more likely to have had an eye test in the last year (42%) and 1-2 years ago (29%), with less than a quarter of people (22%) last having an eye test more than 2 years ago.

In both groups, at Wave 4 a minority of people with PMLD (15%) and without PMLD in Cohort 2 (11%) last had a hearing test within the last 2 years. People most commonly had last had a hearing test more than 2 years ago (46% PMLD; 40% not PMLD), with substantial numbers of people reported to have never had a hearing test (28% PMLD; 19% not PMLD).

Planned medical tests, operations and hospital appointments. At Wave 4, 8% of people with PMLD and 7% of people without PMLD in Cohort 2 had had a medical test cancelled in the last four weeks. Very few people had had a medical operation cancelled in the last four weeks (2% people with PMLD; 0% people without PMLD). Slightly more people had had a hospital outpatient appointment cancelled in the last four weeks (11% people with PMLD; 7% people without PMLD).

At Wave 4, more people with PMLD (28%) compared to people without PMLD in Cohort 2 (17%) were waiting for a medical test or waiting for a hospital outpatient appointment (37% people with PMLD vs 28% people without PMLD). Smaller numbers of people were waiting for an operation (4% people with PMLD vs 8% people without PMLD).

Among those waiting for a medical test, operation or hospital appointment, people in both groups had most commonly been waiting for more than 6 months (>48% of people waiting with PMLD; >39% of people waiting without PMLD).

Annual health checks. Information about annual health checks for people in Cohort 2 with and without PMLD is presented in Figure 4.5 across Wave 3 and Wave 4.

The question asked whether people had had an annual health check since the beginning of the calendar year – 2021 for Wave 3 (where data was largely collected in July/August 2021) and 2022 for Wave 4 (when data were largely collected in September-November 2022). If annual health checks are carried out throughout the calendar year, then fewer people at Wave 3 were likely to have had an annual health check by the time of their interview/survey than people in Wave 4 who were interviewed or surveyed later in the calendar year.

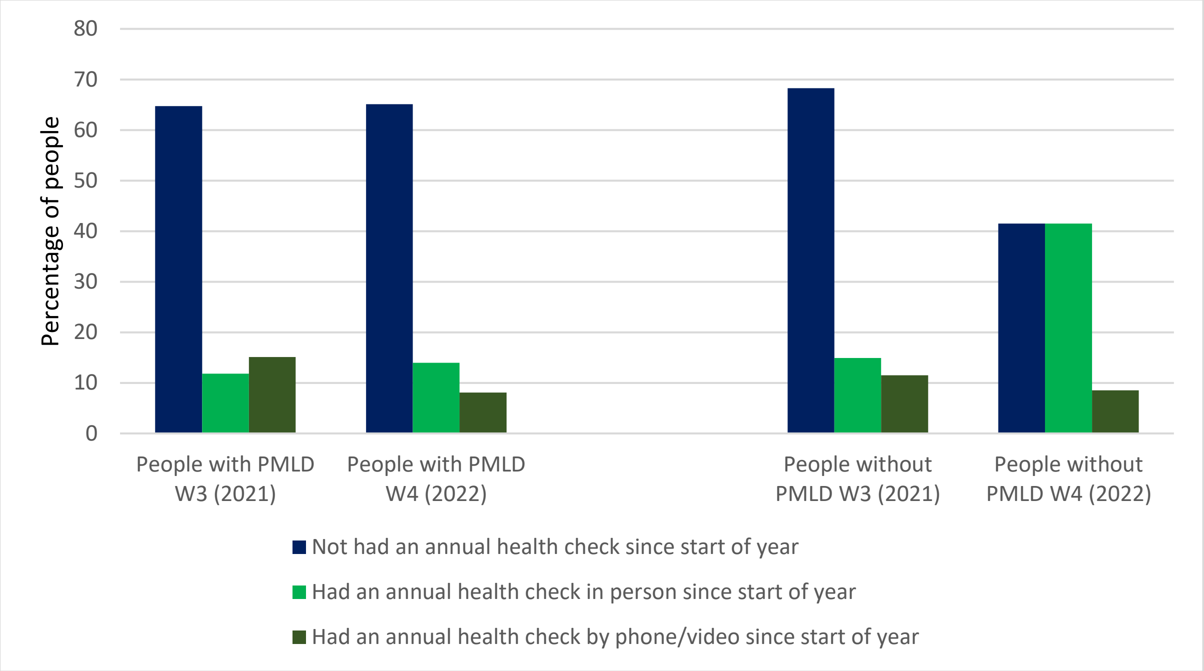

Figure 4.5. Since the start of this year (2021 for Wave 3, 2022 for Wave 4), have you had your annual health check? (percentage of all people in Cohort 2: people with PMLD vs people without PMLD)

As Figure 4.5 shows, at Wave 3 the situation of people with and without PMLD in Cohort 2 was quite similar without respect to annual health checks, with over two thirds of people in both groups not having had an annual health since the start of the year (65% people with PMLD; 68% people without PMLD) and annual health checks roughly evenly split between in person and 'phone/video (largely 'phone) health checks.

By Wave 4, the two groups were in very different situations. For people with PMLD the situation was broadly similar to Wave 3, with over two thirds of people not having had an annual health check since the start of the year (65%) and a mix of in person (14%) and 'phone/video (8%) health checks. For people without PMLD in Cohort 2, their situation was improved at Wave 4, with fewer than half of people not having had an annual health check (42%) and most health checks happening in person (42%) rather than by 'phone/video (12%).

Where people had had health checks at Wave 4, more family carers/support workers rated them as good (42% people with PMLD; 45% people without PMLD) or OK (53% people with PMLD; 41% people without PMLD) than not good (5% people with PMLD; 12% people without PMLD).

Prescribed medication. At Wave 4, 87% of people with PMLD and 77% of people without PMLD in Cohort 2 were taking medications. From Wave 1 to Wave 3, it was rare for either group to report difficulties in getting medications. At Wave 4, for a quarter of people with PMLD (25%) and almost a quarter of people without PMLD (21%) there were difficulties reported in people getting the medications they needed.

4.4. Wellbeing and mental health

We also asked some general questions about the wellbeing of people with learning disabilities in the last four weeks to family carers and support workers of people with and without PMLD, and these data are presented in Figure 4.6 below.

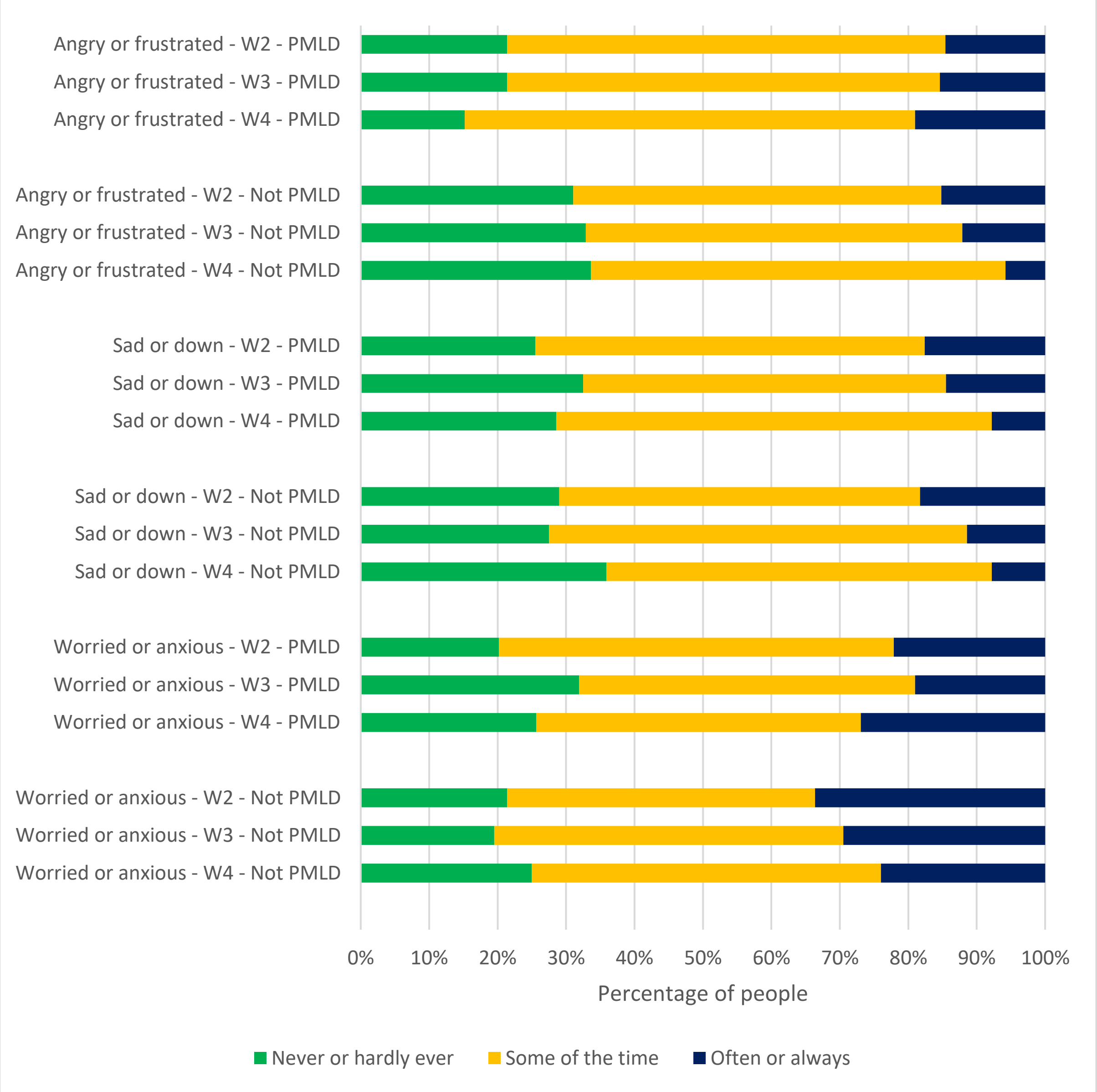

Figure 4.6. How people with learning disabilities have felt in the last four weeks (Cohort 2) – Waves 2, 3 and 4. People with and without PMLD

At Wave 4, more people with PMLD than people without PMLD in Cohort 2 were reported to be angry or frustrated at least some of the time (85% PMLD vs 66% not PMLD), and sad or down at least some of the time (71% PMLD vs 64% not PMLD); similar numbers of people were worried or anxious at Wave 4 (74% PMLD vs 75% not PMLD). On all these indicators there was consistent improvement from Wave 2 to Wave 4 for people without PMLD in Cohort 2. However, while there was some improvement over time for people with PMLD feeling sad or down, there was a worsening trend over time for people with PMLD feeling angry or frustrated, and people with PMLD feeling worried or anxious had been reported to improve from Wave 2 to Wave 3, but had worsened from Wave 3 to Wave 4.

We also asked family carers or support workers of people in Cohort 2 if people with learning disabilities were receiving any support when they are feeling sad, worried, or angry. These data are displayed in Table 4.2 below. Within Cohort 2, people with and without PMLD were broadly similar in the support they were reported to receive, most commonly from family (65% people with PMLD vs 59% people without PMLD) or someone paid to support them (28% people with PMLD vs 34% people without PMLD).

Table 4.2. Support for people with learning disabilities when they are feeling sad, worried or angry (Select all that apply) – Wave 4. Cohort 2 – People with and without PMLD

	People with PMLD	**People without PMLD**
Yes, from a mental health professional	4%	8%
Yes, from someone paid to support them	28%	34%
Yes, from family	65%	59%
Yes, from friends	6%	8%
Yes, from mental health resources (online, videos, information, etc.)	1%	0%
Have not been sad, worried, or angry	11%	10%
Did not seek or get help	12%	15%
Don't know	5%	7%
Prefer not to say	2%	1%

Finally, at Wave 4 we asked family carers and support workers how self-confident they thought the person they were caring for or supporting was; 32% of people with PMLD and 49% of people without PMLD in Cohort 2 were reported to be confident or very confident.

4.5. Relationships, social lives, and digital inclusion

Here we report the findings from questions about the relationships, social lives, and digital inclusion of people with and without PMLD in Cohort 2 at Wave 4.

Staying in touch with family and friends. At Wave 4, we asked whether and how often people with learning disabilities saw family (beyond family members they live with) and friends, with the findings shown in Tables 4.3 and 4.4 below.

Table 4.3. Whether and how often people see family (apart from family members people live with) – Wave 4 – Cohort 2 – People with and without PMLD

	People with PMLD	People without PMLD
Do you ever see anyone in your family?		
Yes	86%	93%
If yes, how often do you see them?		
Every day/nearly every day	16%	7%
A couple of times a week	24%	22%
Every week or nearly every week	38%	44%
About monthly	13%	12%
A few times a year	10%	14%

Table 4.4. Whether and how often people see friends – Wave 4 – Cohort 2 – People with and without PMLD

	Cohort 1	Cohort 2
Do you have friends you like to talk to or do things with?		
Yes	37%	54%
If yes, how often do you see them?		
Every day/nearly every day	7%	16%
A couple of times a week	23%	23%
Every week or nearly every week	36%	34%
About monthly	23%	14%
A few times a year	13%	13%

The vast majority of people with and without PMLD in Cohort 2 stayed in touch in family members (beyond family members they were living with) (86% people with PMLD; 93% people without PMLD), with most people in both groups seeing family at least weekly (78% people with PMLD; 73% people without PMLD).

Fewer people with PMLD (37%) than people without PMLD in Cohort 2 (54%) were reported to have friends they liked to talk or do things with. Among those who did have friends, most people in both groups reported being in contact with friends at least weekly (66% people with PMLD; 73% people without PMLD).

Visitor restrictions. At Wave 4 in Cohort 2, similar proportions of people with and without PMLD living in housing organised by services were reported to have restrictions on visitors (29% people with PMLD vs 24% people without PMLD). At Wave 3 in Cohort 2, more people with PMLD living in housing organised by services were reported to have restrictions on visitors (70%) than people without PMLD in Cohort 2 (49%).

Digital inclusion. We were interested to know what the digital inclusion of people of people with and without PMLD in Cohort 2 was like at Wave 4.

At Wave 4 we asked family carers and support workers about internet usage among people with and without PMLD in Cohort 2. While the vast majority of people with and without PMLD in Cohort 2 had the internet at home (92% people with PMLD; 92% people without PMLD), fewer people with PMLD used the internet (44% people with PMLD; 77% people without PMLD).

We also asked about what people who had the internet where they lived used it for during Wave 4, asking an extended range of questions compared to Wave 3. These data are displayed in Figure 4.7 below.

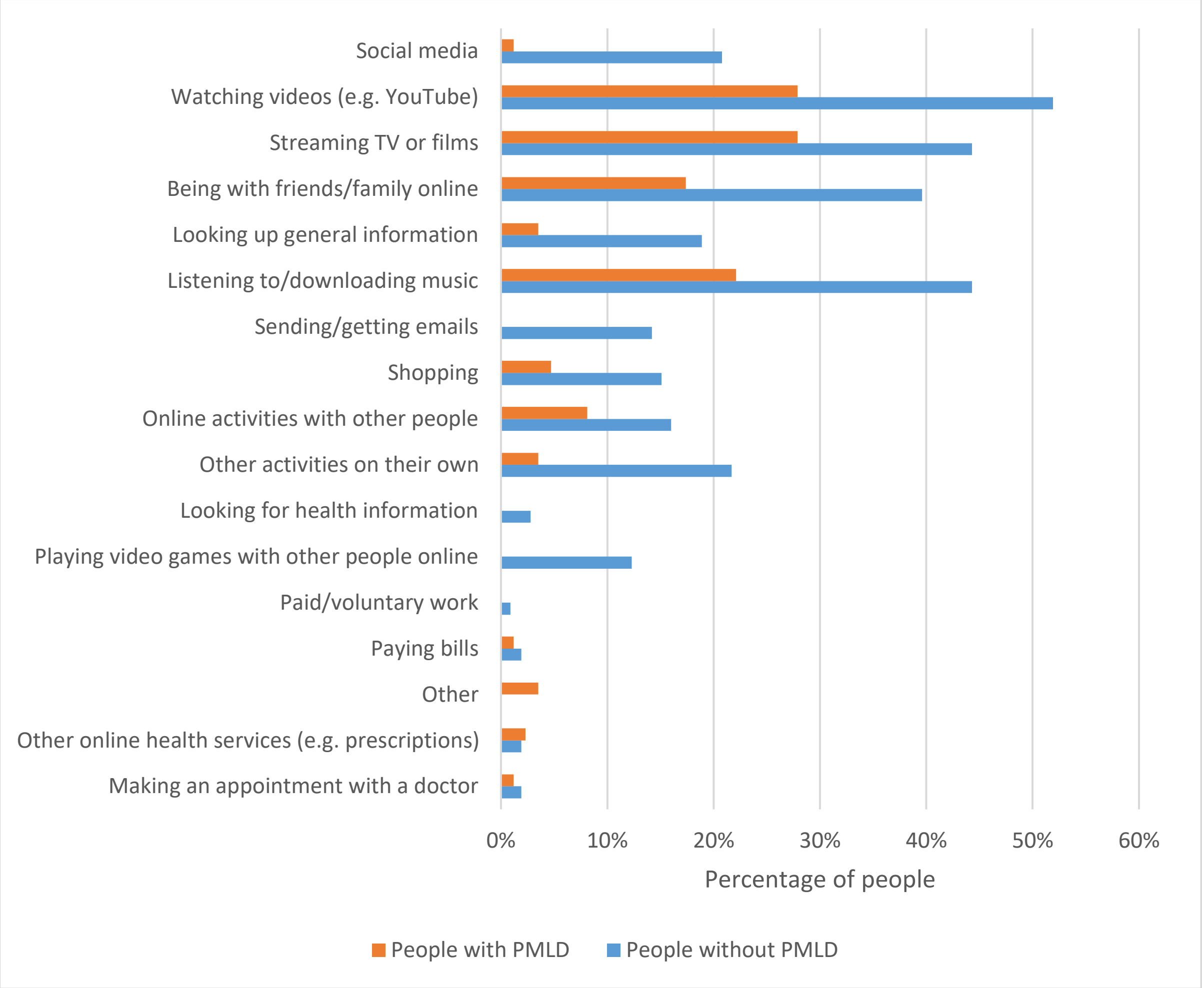

Figure 4.7. What people with learning disabilities currently use the internet for – Wave 4

For both people with and without PMLD in Cohort 2 at Wave 4 the most common uses of the internet were similar, although consistently by many fewer people with PMLD than people without PMLD: watching videos (28% people with PMLD; 52% people without PMLD); streaming TV or films (28% people with PMLD; 44% people without PMLD); listening to/downloading music (22% people with PMLD; 44% people without PMLD); and being with friends/family online (17% people with PMLD; 40% people without PMLD).

4.6 Sources of support

In this sub-section, we report on questions about formal sources of support for people with and without PMLD in Cohort 2 at Wave 4, where there are important differences between these two groups.

Social workers. At Wave 4, similar proportions of people with and without PMLD in Cohort 2 had been in contact with a social worker at the last four weeks; in person (16% people with PMLD vs 15% people without PMLD), or by ‘phone/video call (7% people with PMLD vs 4% people without PMLD). While most people with PMLD (76%) and without PMLD (79%) had not seen a social worker in the last four weeks, more people without PMLD (50%) used to see a social worker compared to people with PMLD (40%).

At Wave 1, 41% of people with PMLD and 34% of people without PMLD in Cohort 2 were reported to regularly see a social worker before the start of the COVID-19 pandemic.

Day services. At Wave 4, similar proportions of people with and without PMLD in Cohort 2 had been to a day service outside their home in the last four weeks (46% people with PMLD; 41% people without PMLD). At Wave 4, 9% of people with PMLD and 6% of people without PMLD could not or did not want to use a day service that was open. At Wave 4 in Cohort 2, people with and without PMLD used a day service for broadly similar numbers of days per week (up to 1 day a week – 21% people with PMLD vs 23% people without PMLD; 2-3 days a week – 38% people with PMLD vs 30% people without PMLD; 4 or more days a week – 41% people with PMLD vs 48% people without PMLD).

At Wave 1, 69% of people with PMLD and 54% of people without PMLD in Cohort 2 were reported to regularly go to a day service before the start of the COVID-19 pandemic.

Community activities. At Wave 4, fewer people with PMLD (47%) than people without PMLD in Cohort 2 (68%) had gone to a community activity outside their home in the last four weeks. However, among those who did go to community activities, people with PMLD were more likely to do this on more days per week than people without PMLD in Cohort 2 (up to 1 day a week – 33% people with PMLD vs 40% people without PMLD; 2-3 days a week – 33% people with PMLD vs 46% people without PMLD; 4 or more days a week – 33% people with PMLD vs 14% people without PMLD).

At Wave 1, 78% of people with PMLD and 87% of people without PMLD in Cohort 2 were reported to regularly go to community activities before the start of the COVID-19 pandemic.

Going out of the house with personal assistants/support workers. At Wave 4, a majority of people with PMLD (55%) and without PMLD in Cohort 2 (62%) had been going out of the house with PAs/support workers in the last four weeks. Among the people who went out with a PA or support worker, people with PMLD did this for fewer days per week than people without PMLD in Cohort 2 (up to 1 day a week – 34% people with PMLD vs 25% people without PMLD; 2-3 days a week – 19% people with PMLD vs 25% people without PMLD; 4 or more days a week – 47% people with PMLD vs 50% people without PMLD).

At Wave 1, 78% of people with PMLD and 73% of people without PMLD in Cohort 2 were reported to regularly go out of the house with a PA/support worker before the start of the COVID-19 pandemic.

Further education. At Wave 4, 9% of people with PMLD and 14% of people without PMLD in Cohort 2 had attended further education outside their home in the last four weeks.

Short breaks/respite. Figure 4.8 below presents data about whether those people with or without PMLD in Cohort 2 living with their families at Waves 2, 3 and 4 had gone to a short break/respite service in the four weeks before each survey. At Wave 4, 24% of people with PMLD and 30% of people without PMLD in Cohort 2 had gone to a short break/respite service in the last four weeks. The proportion of people in both groups going to a short break or respite service increased from Wave 2 to Wave 4, but at a faster rate for people without PMLD compared to people with PMLD.

At Wave 1, 46% of people with PMLD and 34% of people without PMLD in Cohort were reported to regularly use short break/respite services before the COVID-19 pandemic.

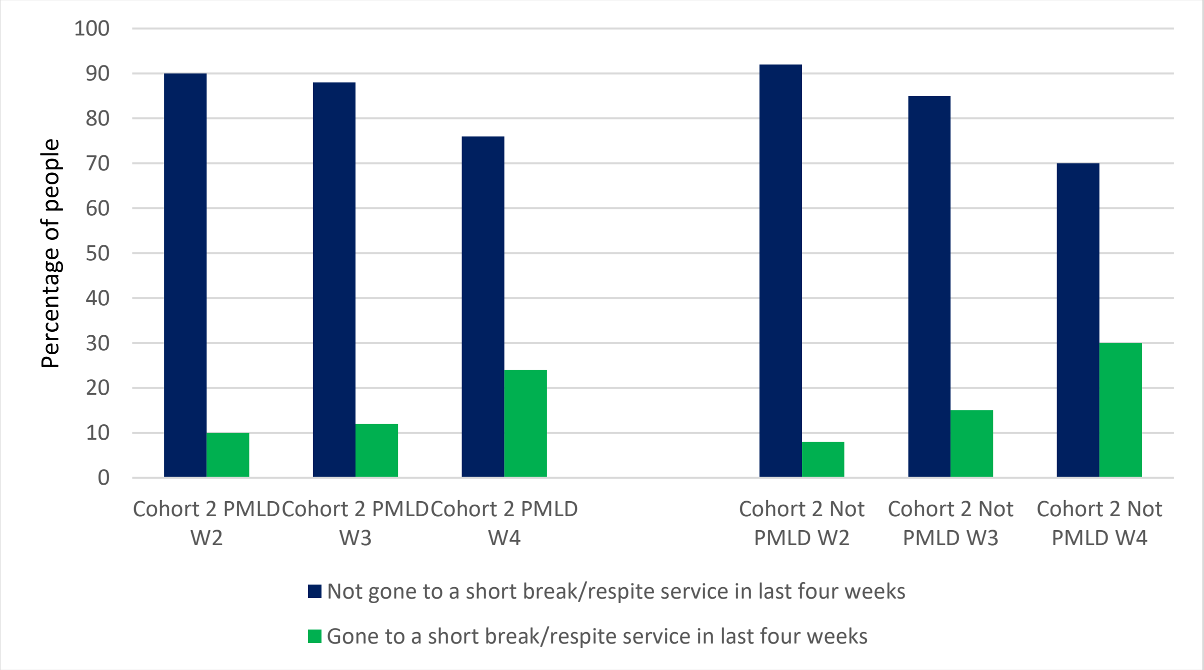

Figure 4.8. For those people living with families, going to a short break/respite service in the last four weeks: Waves 2, 3 and 4. Cohort 2 – People with and without PMLD

Personal assistants/support workers helping at home. Figure 4.9 below presents data about whether people with and without PMLD in Cohort 2 at Waves 2, 3 and 4 had been getting help at home from PAs/support workers in the four weeks before each survey.

At Wave 4, more people with PMLD (62%) than people without PMLD in Cohort 2 (49%) had been getting help from PAs/support workers at home in the last four weeks. This difference between groups was evident at Waves 2, 3 and 4, although there were some signs of a decrease in the number of people with PMLD getting this help over time while the proportion of people without PMLD getting this help stayed static over time.

At Wave 1, 71% of people with PMLD and 52% of people without PMLD in Cohort 2 were reported to be getting regular help at home from PAs/support workers.

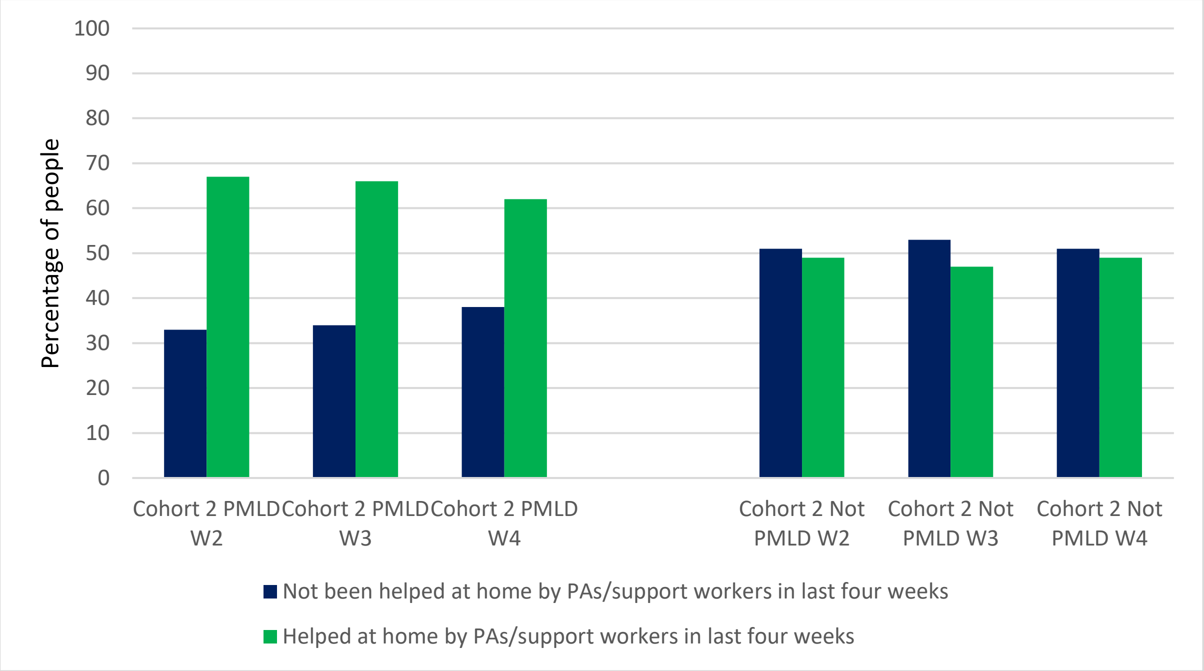

Figure 4.9. Being helped by PAs/support workers in the person's home in the last four weeks: Waves 2, 3 and 4. Cohort 2 – People with and without PMLD

At Wave 4, fewer people with PMLD (44%) than people without PMLD in Cohort 2 (69%) were getting help at home from a PA/support worker for more than 5 days a week.

At Wave 4, more people with PMLD (42%) than people without PMLD in Cohort 2 (29%) were reported to have had a PA or support worker who helped the person at home leave their job in the last four weeks.

Finally, at Wave 4 we asked family carers whether in the last four weeks they had had to step in and carry out work previously done by a paid support worker – more family carers of people with PMLD (53%) than family carers of people without PMLD (37%) said this was the case.

4.7. Living circumstances and money

In this sub-section, we report findings from Wave 4 questions about the living circumstances, and money of people with and without PMLD in Cohort 2 during the COVID-19 pandemic.

Leaving the house and getting around. We asked about the reasons people with and without PMLD went outside their home during the week before the survey at Wave 4, presented in Figure 4.10 for people with and without PMLD in Cohort 2.

The most frequent reasons for going outside the house in the last seven days were similar for people with and without PMLD at Wave 4: going out in a private car (62% people with PMLD; 82% people without PMLD); going to a park or local green space (54% people with PMLD; 54% people without PMLD); shopping for food, medicine and everyday things (42% people with PMLD; 65% people without PMLD); going to a café, bar or restaurant (42% people with PMLD ; 63% people without PMLD). However, for almost all reasons far fewer people with PMLD were going outside their house than people without PMLD, the only exceptions being going to a park or local green space (54% people with PMLD; 54% people without PMLD) and going to a place of worship (13% people with PMLD; 9% people without PMLD).

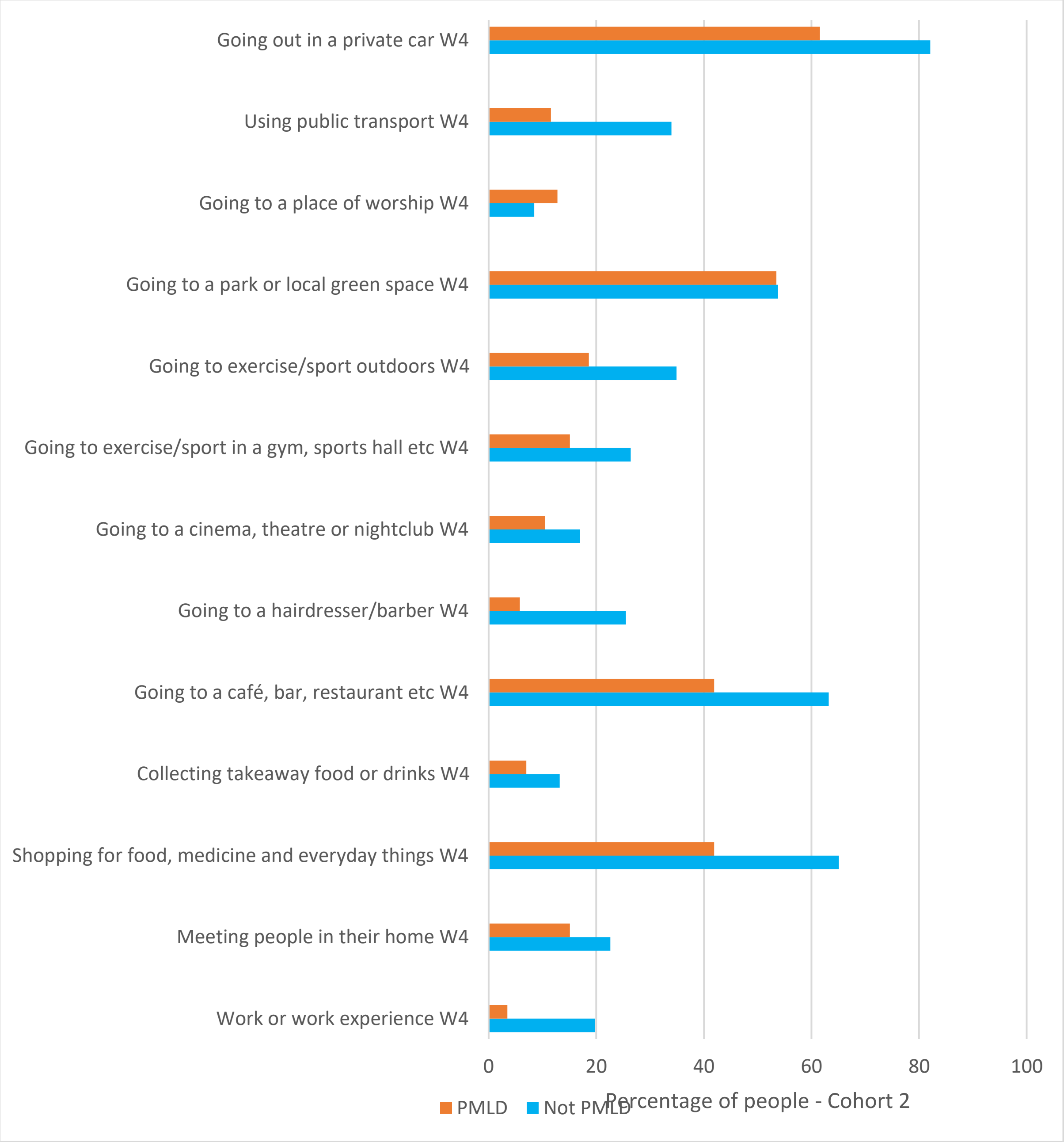

Figure 4.10. Reasons that people with learning disabilities went outside of their house in the last week – Wave 4 – Cohort 2 – People with and without PMLD

In Wave 4, we also asked family carers and support workers of people with and without PMLD in Cohort 2 some additional questions about how people got around, and what support people needed to go out.

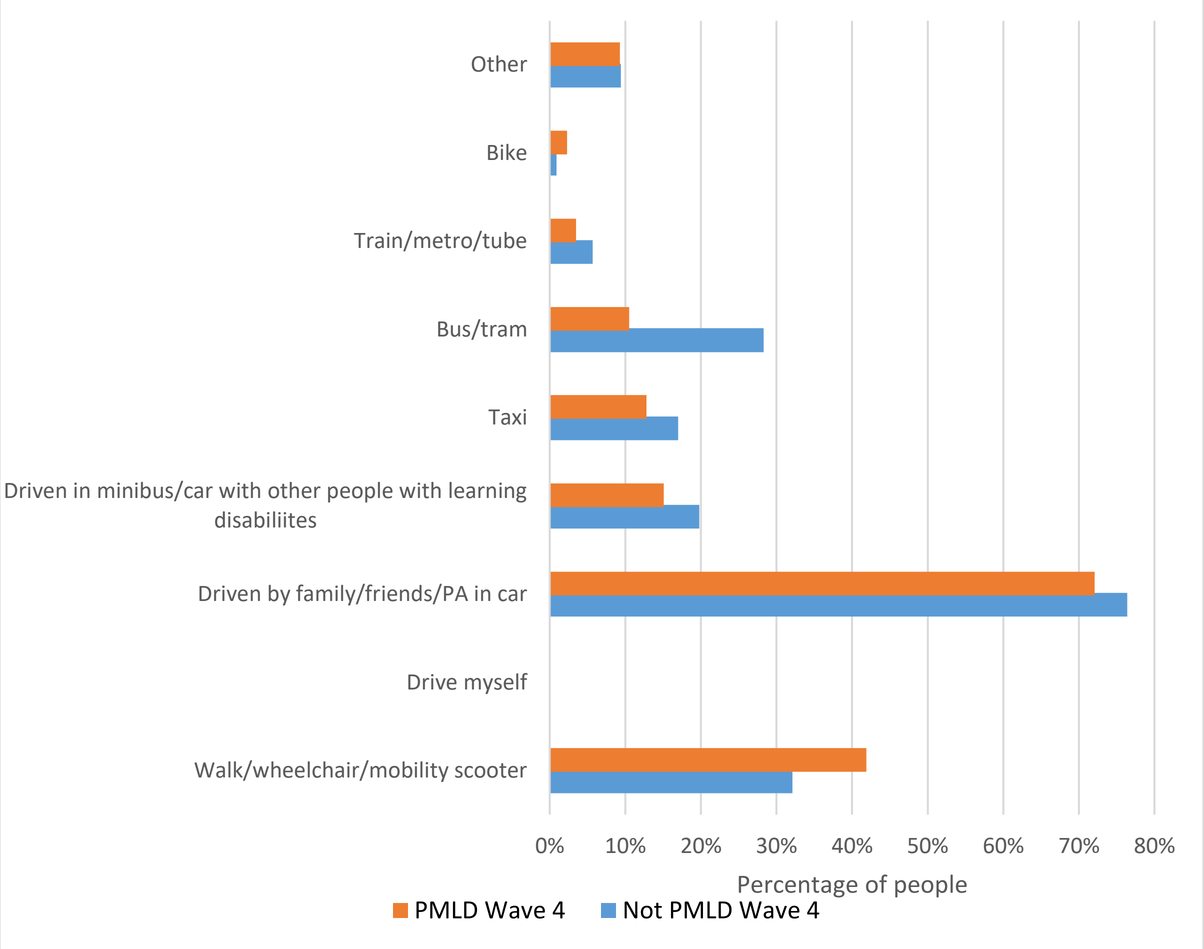

Figure 4.11. Ways that people usually get to places –Cohort 2 – People with and without PMLD - Wave 4

Figure 4.11 shows that by far the most common way of usually getting to places for both people with and without PMLD in Cohort 2 was being driven by family/friends/PA in a car (72% people with PMLD; 76% people without PMLD), followed by travelling by walking/wheelchair/mobility scooter (42% people with PMLD; 32% people without PMLD). For most modes of getting out, people without PMLD were slightly more likely than people with PMLD to use them, with a larger difference apparent in the use of a bus/tram (11% people with PMLD; 28% people without PMLD).

At Wave 4, very few people with PMLD (1%) or without PMLD in Cohort 2 (6%) were reported to feel safe on public transport, with a further 27% of people with PMLD and 47% of people without PMLD reported to feel safe only if someone was with them and a further 2% of people with PMLD and 12% of people without PMLD reported to only feel safe in the daytime. At Wave 4, more people with PMLD (18%) than without PMLD (6%) were reported to never use public transport.

When asked if people usually needed someone to go with them when they wanted to go somewhere, the vast majority of people with PMLD (95%) and without PMLD in Cohort 2 (85%) were reported to need someone.

For those who needed someone to go with them when they wanted to go somewhere (at least some of the time), 41% of people with PMLD and 49% of people without PMLD in Cohort 2 had someone usually around to help. For almost a third of people with PMLD (33%) and without PMLD (30%), all outings had to be planned in advance.

Local neighbourhoods. At Wave 4, we asked family carers and support workers of people in Cohort 2 whether the person with or without PMLD liked living in their neighbourhood. A substantial majority in both groups was reported to like living in their neighbourhood, although this was lower for people with PMLD (75%) than people without PMLD (90%). It is important to note that more family carers and support workers of people with PMLD (21%) than people without PMLD (10%) said that they did not know whether the person they were supporting/caring for liked living in their neighbourhood.

Paid employment and voluntary work. At Wave 4, no-one with PMLD and 9% of people without PMLD in Cohort 2 were reported to have a part-time paid job, with almost everyone in work (90%) working for less than 16 hours per week and reported to like their job (78%).

In terms of voluntary work, at Wave 4 4% of people with PMLD and 17% of people without PMLD in Cohort 2 were reported to be doing voluntary work, mostly at least once a week.

4.7 Money

At all four waves, we asked family members or support workers of people with and without PMLD in Cohort 2 if the person with learning disabilities they were caring for/supporting had enough money at the moment. The results are presented in Figure 4.12 below.

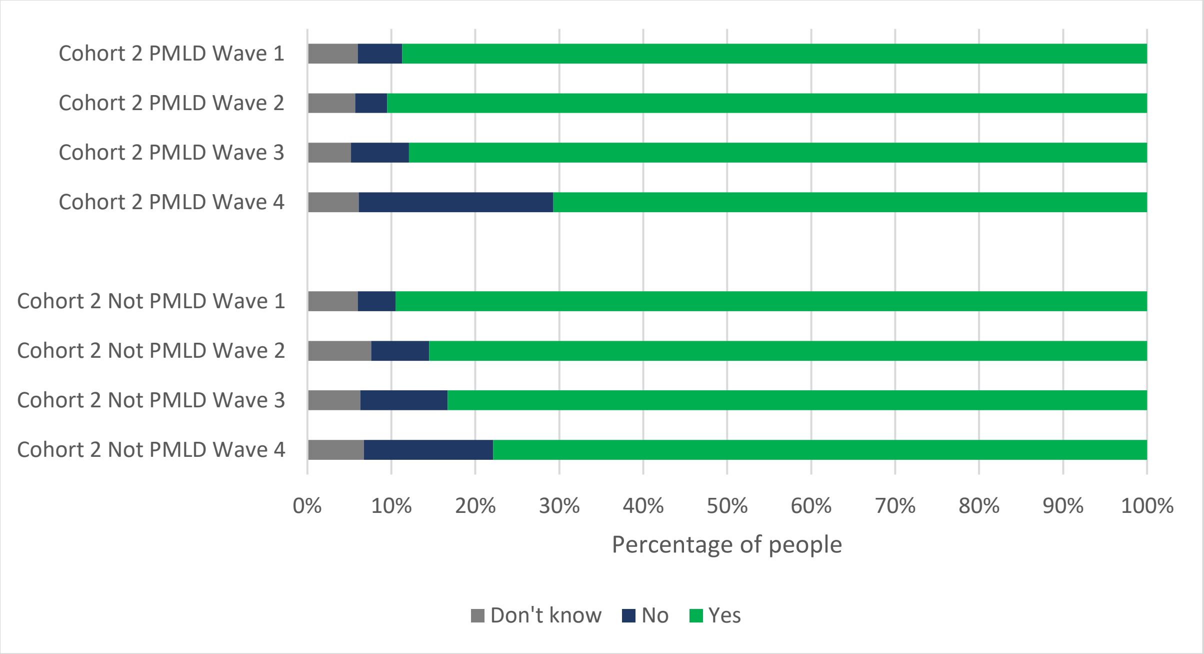

Figure 4.12. Does the person you support/care for have enough money at the moment? (Waves 1, 2, 3, 4 Cohort 2 People with and without PMLD)

For both people with and without PMLD, the proportion of people <u>without</u> enough money at the moment was reported by family carers and support workers to increase over time from Wave 1 to Wave 4, from relatively low levels at Wave 1 (5% people with PMLD; 5% people without PMLD). For people without PMLD, the increase was steady over time, to 15% of people reported to not have enough money at Wave 4. For people with PMLD, there was a particularly sharp increase in the proportion of people not having enough money from Wave 3 (7%) to Wave 4 (23%), with almost a quarter of people with PMLD at Wave 4 reported not to have enough money at the moment.

At Wave 4, we also asked family carers or support workers of people in Cohort 2 if in the last four weeks there had been enough household money for a range of things when the person with learning disabilities wanted them, ranging from energy for heating and lighting through to holidays. Figure 4.13 presents this information.

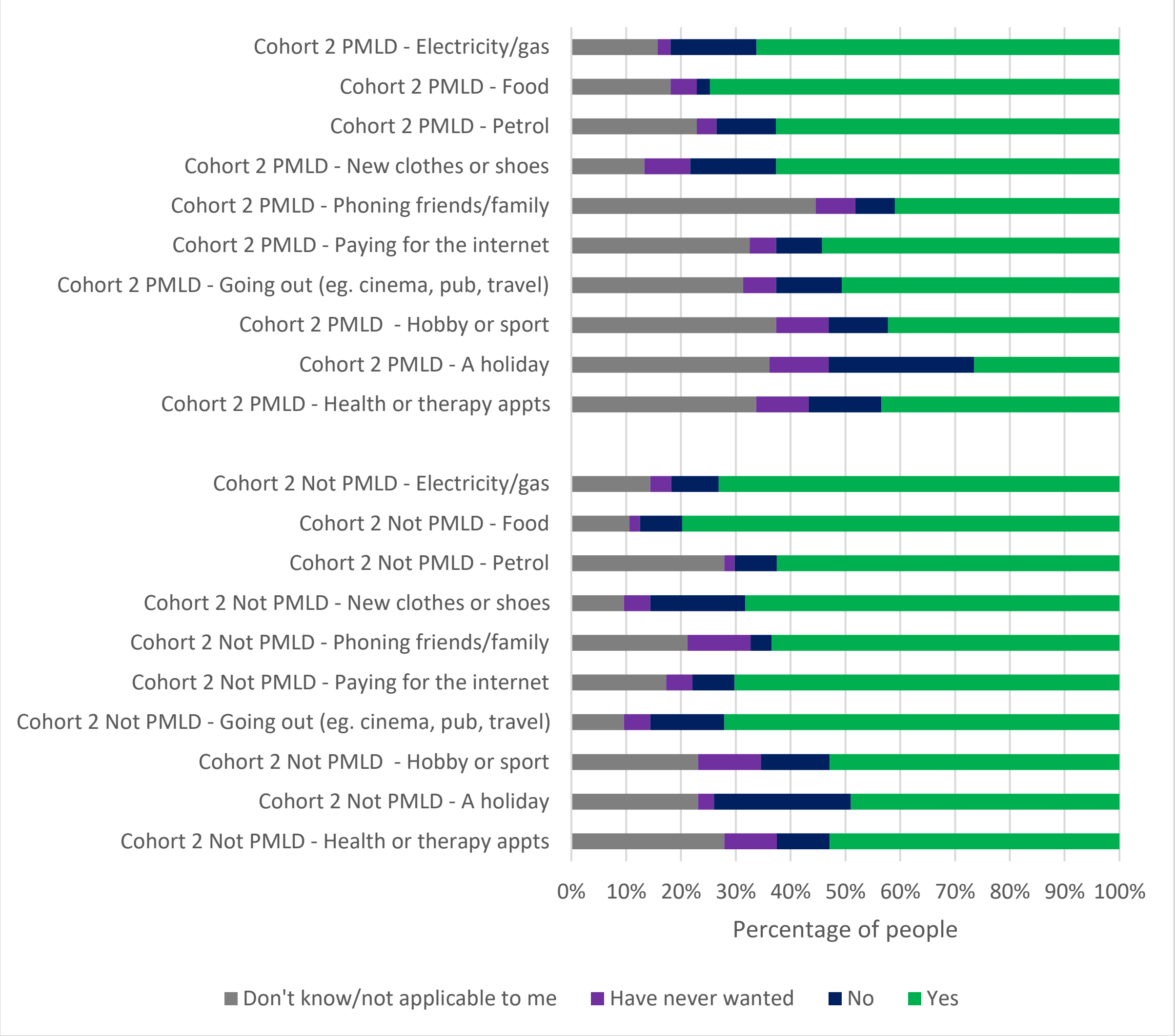

Figure 4.13. Has there been enough money in the household in the last four weeks for these things when the person with learning disabilities wants them? (Cohort 2 Wave 4 People with and without PMLD)

For both groups in Cohort 2, relatively large proportions of family carers or support workers reported that they did not know about money for a wide range of things or that the question was not applicable to the person they were caring for/supporting, possibly because Cohort 2 respondents were not always living in the same place as the person with learning disabilities or respondents would not always know the details of the financial situation for people.

Family carers/support workers of both groups in Cohort 2 most commonly said that the person they were caring for/supporting did not have enough money for a holiday (27% people with PMLD; 25% people without PMLD), new clothes or shoes (16% people with PMLD; 17% people without PMLD), going out (12% people with PMLD; 14% people without PMLD), a hobby/sport (11% people with PMLD; 13% people without PMLD), electricity/gas (16% people with PMLD; 9% people without PMLD) and health or therapy appointments (13% people with PMLD; 10% people without PMLD), suggesting pervasive cost of living restrictions on the lives of some people with learning disabilities in both groups in Cohort 2.

4.8. Future considerations

Life returning to normal. We asked family carers and support workers of people with and without PMLD in Cohort 2 about when they thought the life of the person they support/care for will return to normal – Figure 4.14 presents these data for people with and without PMLD in Cohort 2.

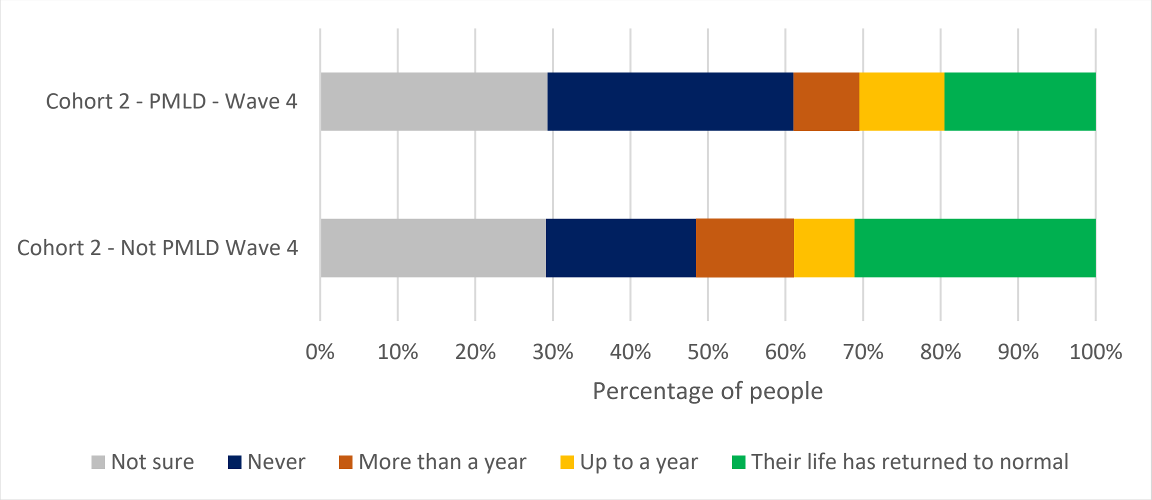

Figure 4.14 How long do you think it will be before the life of the person you support/care for returns to how it was before the COVID-19 pandemic? Cohort 2 Wave 4 People with and without PMLD.

For both groups, under a third of family carers/support workers at Wave 4 were not sure when the life of the person they supported/cared for would return to normal (29% PMLD; 29% Not PMLD). For family carers/support workers of people with PMLD, the most common response was that the person's life would never return to normal (32%), with fewer family carers/support workers saying that the person's life had already returned to normal (20%). For family carers/supporters of people without PMLD in Cohort 2, the most common response was that the person's life had already returned to normal (31%), with fewer family carers/support workers saying that the person's life would never return to normal (19%).

4.9. The health and wellbeing of family carers

In this subsection, we describe the results of questions for participants in Cohort 2 that related specifically to the health and well-being of family carers of people with and without PMLD. In this section, we focus specifically on family carers rather than on family carers and support workers in Cohort 2 as a whole.

Happiness and anxiety. We asked about the health and wellbeing of family carers across all four waves of the project. First, we asked family carers how happy they were feeling the day before completing the survey (0-10 scale where 10 is the happiest) and how anxious they were feeling the day before completing the survey (0-10 scale where 10 is the most anxious). Mean scores at each wave for family carers of people with and without PMLD in Cohort 2 are presented in Figure 4.15 below.

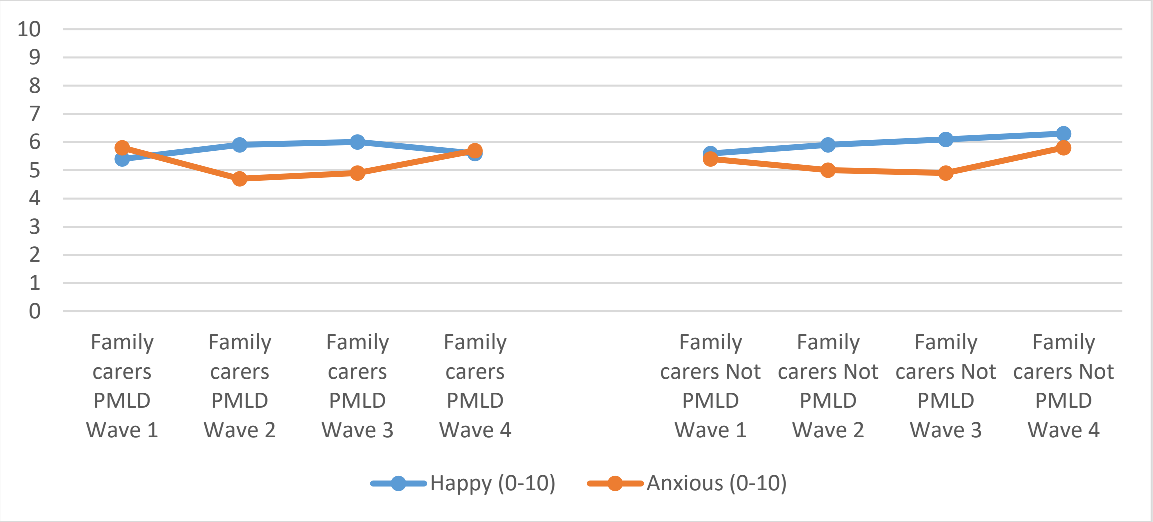

Figure 4.15: Mean happiness and anxiety scores for family carers of people with and without PMLD in Cohort 2– Waves 1, 2, 3 and 4

Family carer mean scores on happiness were 5.6 at Wave 1 and 6.3 at Wave 4 for family carers of people without PMLD. Family carer mean scores on happiness for family carers of people with PMLD were 5.4 at Wave 1 and 5.6 at Wave 4 (mean 5.6).

Family carer mean scores on anxiety were fairly consistent over time for both groups (Wave 4 mean 5.7 family carers of people with PMLD; mean 5.8 family carers of people without PMLD in Cohort 2).

Self-reported health. We also asked family carers about their self-reported health in general at the moment, again across all four waves, reported in Figure 4.16 below.

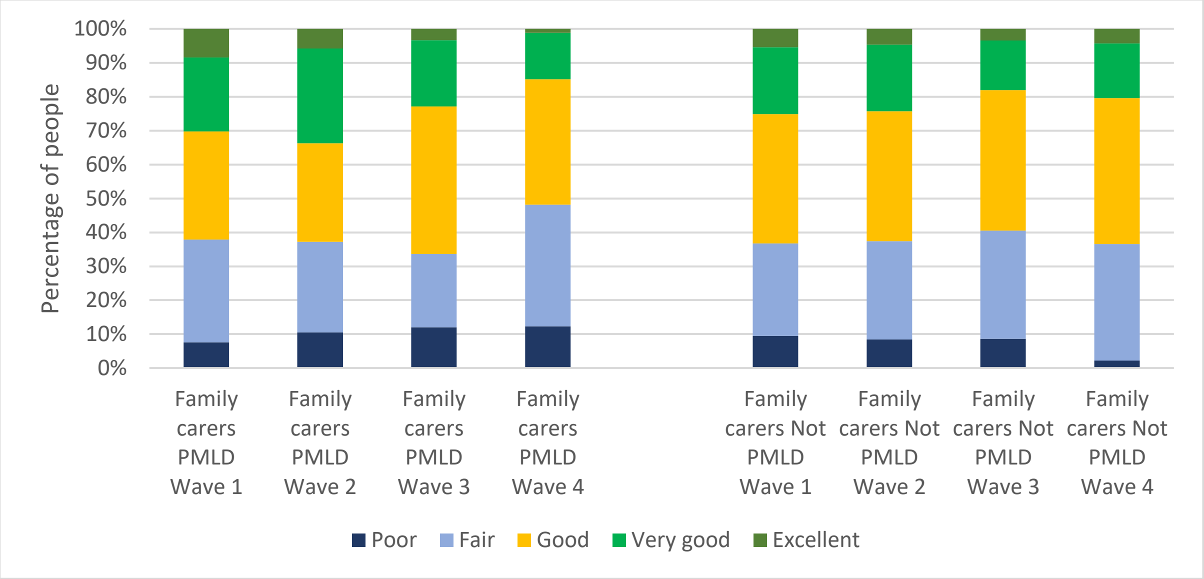

Figure 4.16: How is your health in general? Family carers of people with and without PMLD in Cohort 2, Waves 1, 2, 3 and 4

The self-reported general health of family carers of people with PMLD generally worsened from Wave 1 to Wave 4. By Wave 4, 15% of family carers of people with PMLD rated their health as excellent or very good, compared to 30% at Wave 1 (during a national lockdown). Also at Wave 4, 48% of family carers of people with PMLD at Wave 4 rated their health as fair or poor, compared to 38% at Wave 1.

The trend over time was less clear for family carers of people without PMLD in Cohort 2. At Wave 4, 20% of family carers of people without PMLD rated their health as excellent or very good, compared to 25% at Wave 1. Also at Wave 4, 37% of family carers of people without PMLD at Wave 4 rated their health as fair or poor, compared to 37% at Wave 1.

Impact of the caring role on the health of family carers. Finally, we asked specifically about what effect their caring role had had on the health and wellbeing of family carers of people with and without PMLD in the last four weeks, and these data are presented in Figure 4.17 below.

Family carers' reports of the impact of the caring role on their health, including trends over time, are different for family carers of people with PMLD and people without PMLD in Cohort 2.

For the three most commonly reported impacts, the proportions of family carers with and without PMLD reporting each impact were broadly similar at Wave 1 (Wave 1: Feeling tired 56% PMLD vs 61% not PMLD; General feeling of stress 59% PMLD vs

59% not PMLD; disturbed sleep 53% PMLD vs 55% not PMLD). By Wave 4, the proportion of family carers of people without PMLD reporting these impacts had increased or decreased only slightly over time, while the proportion of family carers of people with PMLD reporting these impacts had increased markedly by Wave 4 (Wave 4: Feeling tired 77% PMLD vs 69% not PMLD; General feeling of stress 71% PMLD vs 59% not PMLD; disturbed sleep 63% PMLD vs 51% not PMLD). A similar pattern was evident for feeling short tempered/irritable (Wave 1: 35% PMLD vs 32% not PMLD; Wave 4 40% PMLD vs 32% not PMLD).

Starting from similar proportions of family carers in both groups reporting an impact of the caring role on feeling depressed at Wave 1 (38% PMLD vs 41% not PMLD), the proportion decreased substantially for family carers of people without PMLD by Wave 4 (30% not PMLD) while it increased substantially for family carers of people with PMLD by Wave 4 (51% PMLD).

For three further impacts, the proportion of family carers of people with PMLD reporting the impact was consistently higher throughout compared to family carers of people without PMLD in Cohort 2, with larger increases over time among family carers of people with PMLD than family carers of people without PMLD (Physical strain: 34% Wave 1 – 48% Wave 4 PMLD vs 17% Wave 1 – 19% Wave 4 not PMLD; Made an existing condition worse: 21% Wave 1 – 27% Wave 4 PMLD vs 16% Wave 1 – 20% Wave 4 not PMLD; Developed my own health conditions: 13% Wave 1 – 24% Wave 4 PMLD vs 7% Wave 1 to 12% Wave 4 not PMLD). The proportion of family carers of people with PMLD contacting their own GP in the last four weeks fluctuated over time with no consistent trends (11% Wave 1 – 13% Wave 4), whereas this had decreased by Wave 4 for family carers of people without PMLD in Cohort 2 (11% Wave 1 – 6% Wave 4).

By Wave 4, only 6% of family carers of people with PMLD and 10% of family carers of people without PMLD in Cohort were reported that none of the listed impacts of their caring role on their health applied to them.

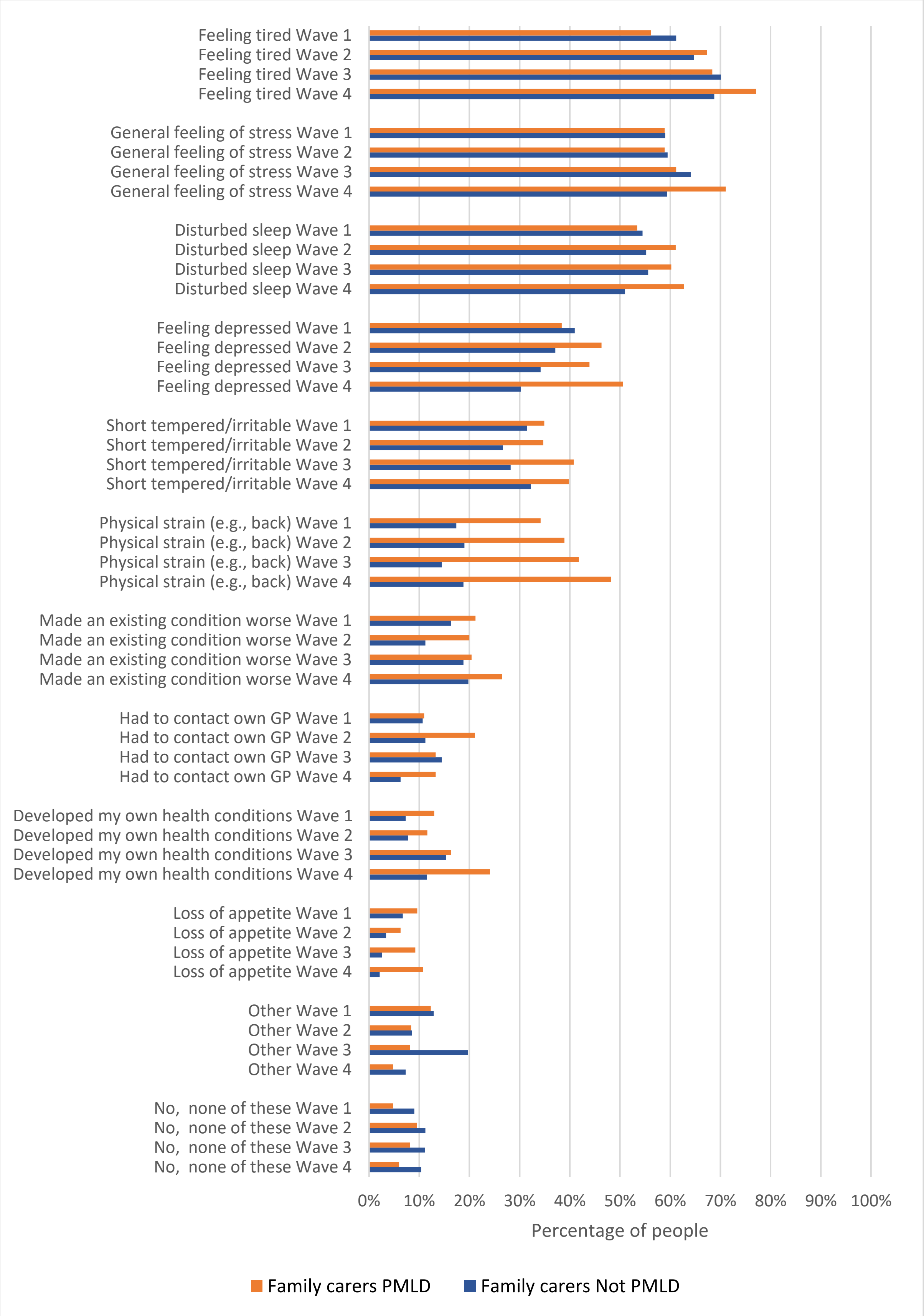

Figure 4.17. In the last four weeks, has your health been affected by your caring role in any of these ways? (Select all that apply) Family carers of people with and without PMLD, Waves 1, 2, 3 and 4

Version 2.0, February 2023