

March 2023



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



This report is about a research study about coronavirus and people with learning disabilities.

We have asked people questions for the research 4 times over 2 years (since September 2020).



The last time we asked people questions was between September and December 2022.



This report is about what we have found out the 4<sup>th</sup> time we talked to people.



We talked to 355 adults with learning disabilities. We talked to people living in England, Wales, Scotland and Northern Ireland.

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192 family carers or paid supporters of people who couldn't take part in an interview with us also gave us information. Some of those people had profound multiple learning disabilities (sometimes called PMLD).

People told us about a lot of things. This report will talk about 8 important things from the research:

- 1. Coronavirus is still in people's lives
- 2. Life is getting back to normal for some people
- 3. Some things have got better for some people
- Support from services has not gone back to how it was before coronavirus
- 5. For some people, daily life is an increasing struggle
- 6. It is a difficult time for many family carers
- 7. Things looked worse for people with PMLD and their carers
- 8. Unfair lives are becoming more unfair

# %

In this report we use percentages to explain how many people have told us about things. If we say 100%, it means everybody, if we say 50% it means half of people and 0% means no-one.

### 1. Coronavirus is still in people's lives



Over 60% of people have had coronavirus. This is a lot more people than last time we talked to people in the Summer of 2022.



Most people (over 80%) have had 3 or 4 coronavirus vaccinations.



People told us that about 40% of people had done a coronavirus test in the last four weeks.



People were still doing things to stay safe from coronavirus like washing their hands more often and wearing masks when out.



Only a few people (less than 2%) were still shielding.



Just under half (49%) of people were still worried about getting coronavirus. Most people (74%) were still worried about giving coronavirus to friends and family. This was less than any of the other times we talked to people.

# 2. Life is getting back to normal for some people



42% of the people we spoke to said their lives had gone back to normal. Family members or paid carers said life had gone back to normal for 26% of people they support.



26% of people we talked to said they weren't doing anything to keep themselves safe from coronavirus.



39% of people we talked to and 31% of family carers or paid supporters said they had not wanted to find out any information about coronavirus recently.

# 3. Some things have got better for some people



People's mental health is gradually getting better.



Many people were still enjoying using the internet mostly for fun and to connect with other people.



Since last time we spoke to people, more people were going out of the house for lots of different reasons.

## 4. Support from services has not gone back to how it was before coronavirus



The number of people seeing a GP, community nurse, social worker or other health professional is about the same as when we talked to them in the Summer of 2022.



Appointments are more often in person now.



45% of people found it easy to see their GP when they needed to.



Community activities, respite, paid support at home and going to day services have increased over time. People were doing more of these activities before coronavirus.

## 5. For some people, daily life is an increasing struggle



14% people we talked to and 19% of family members or paid carers who completed the survey told us they don't have enough money now. More people do not have enough money now than when we started the research.



More people told us that they were having difficulty getting their medication (11% of people we talked to, and 23% of family members or paid supporters who did the survey).



22% of people that we talked to and 36% of people whose family member or paid carer completed a survey had their PA or support worker leave their job recently.

# 6. It is a difficult time for many family carers



Family carers were less happy and more anxious than most other people in Great Britain.



Family carers' health has generally been getting worse since the research started in December 2020.



Most family carers feel tired (73%), stressed (65%), or don't sleep very well (56%).



45% of family carers said they had had to do some caring that used to be done by a paid support worker.

## 7. Things looked worse for people with PMLD and their carers



The health of people with PMLD was worse than other groups of people with learning disabilities. The health of people with PMLD has got worse since the research started.



Fewer people with PMLD left their house compared to other people with learning disabilities.



32% of carers of people with PMLD said that the person's life would never get back to normal.



30% of carers of people with PMLD were still wearing some form of PPE.

### 8. Unfair lives are becoming more unfair



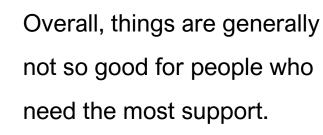
About 50% of people said their health wasn't as good as it had been before coronavirus.



Less people are doing voluntary work now (43% of people) compared to before coronavirus when it was 50%.



36% of people we talked to had a paid job. 2% of people whose family member or paid carer completed a survey had a paid job. The number of people with paid jobs is similar to before coronavirus.







#### If you want more information or have any

questions, please contact the researchers:





The National Institute for Health and Care Research paid for us to do this research. This report is written by the research team, not the NIHR.