



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

### **Wave 2 Results - July 2021**

#### **Briefing: Impact of caring for people with learning disabilities during the COVID-19 pandemic**

##### **Background**

- This study is designed to systematically and responsively track the experiences of adults with learning disabilities through the COVID-19 pandemic across the four UK nations.
- There will be three 'Waves' of data collection over a 12-month period. Wave 2 data were collected between April and May 2021.
- The data in this briefing are taken from Wave 2 of the study. If you want to find out more detail about the people who took part and the Wave 1 findings, you can download the full report [here](#).
- There are two 'Cohorts' of participants in this study. In Wave 2:
  - In Cohort 1, 598 adults with learning disabilities were interviewed by researchers.
  - In Cohort 2, family carers or paid support staff took part in an online survey about the experiences of 272 adults with learning disabilities who they supported/cared for. These were likely to be adults with more severe to profound learning disabilities.
  - In Cohort 2, 114 of the adults were described as having profound and multiple learning disabilities (PMLD).
- This document presents selected data about the impact of the COVID-19 pandemic on caring for people with learning disabilities. It comes from data for those carers who completed both Wave 1 and Wave 2 of the study (244 carers). These data only relate to people in Cohort 2. You can download the Easy Read briefing about the impact of caring for people with learning disabilities [here](#).

## **Health of carers**

- The majority (69%) of family carers and paid support staff of people with learning disabilities in Cohort 2 reported that their health was excellent, very good, or good at the time of the survey.
  - At Wave 1, the majority (64%) of family carers and paid support staff of people with learning disabilities in Cohort 2 rated their health as excellent, very good, or good.

## **Mental wellbeing of carers**

- On a scale of 0 to 10, with 0 being “not at all happy” and 10 being “completely happy”, family carers and paid support staff of people with learning disabilities rated their happiness as an average score of 6.2 at the time of the second survey.
  - At Wave 1, family carers and paid support staff of people with learning disabilities in Cohort 2 rated their happiness as an average score of 5.8 at the time of the survey.
  - This question is also answered by a sample of adults in Great Britain by the Office for National Statistics in their Opinions and Lifestyle Survey every week. Between the beginning of April and end of May 2021, which was the same timescale as data collection for Wave 2, weekly happiness scores ranged from 6.9 to 7.1.
- On a scale of 0 to 10, with 0 being “not at all anxious” and 10 being “completely anxious”, family carers and paid support staff of people with learning disabilities rated their anxiety as an average score of 4.8 at the time of the survey.
  - At Wave 1, family carers and paid support staff of people with learning disabilities in Cohort 2 rated their anxiety as an average score of 5.5 at the time of the survey.
  - This question is also answered by a sample of adults in Great Britain by the Office for National Statistics in their Opinions and Lifestyle Survey every week. Between the beginning of April and end of May 2021, which was the same timescale as data collection for Wave 2, weekly anxiety scores ranged from 3.8 to 3.9.

## **The impact of caring on health**

- At Wave 2, 90% of family carers and paid support staff of people with learning disabilities in Cohort 2 reported that their health had been affected by their caring role in some way in the last four weeks.
- Figure 1, below, shows the most frequently reported ways that carers' health was affected by their caring role in the last four weeks.

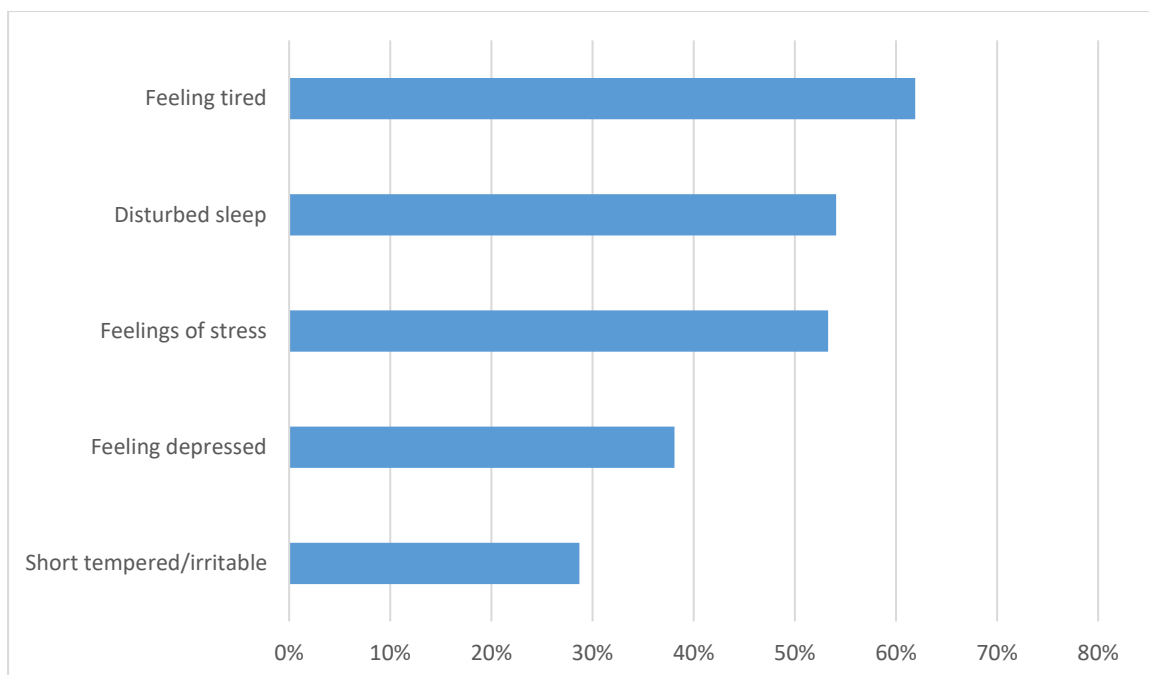


Figure 1. The most frequently reported ways that the health of family carers and paid support staff had been affected by their caring role in the last four weeks

- At Wave 1 the most common reported effects of caring were general feelings of stress (66%), feeling tired (61%), disturbed sleep (59%), feeling depressed (40%), and being short-tempered or irritable (36%).
- This question was also asked in the Personal Social Services Survey of Adult Carers in England 2018-19. In that survey, in the sub-sample of 10,450 family carers of adults with learning disabilities, the most frequent response to this question was 'No, none of these' (26%).
  - The five most frequently reported ways in which family carers' health had been affected were that they developed their own health condition (23%), had to see their own GP (22%), had a general feeling of stress (21%), had physical strain (e.g., their back) (21%), and a loss of appetite (20%).
  - The carers in this study were therefore reporting larger effects of caring on their health than those in the Personal Social Services Survey of Adult Carers in England 2018-19.

### Changes to wellbeing over time

- Family carers and paid support staff of people with learning disabilities in Cohort 2 were asked questions about their wellbeing at Wave 1 (December 2020-February 2021) and Wave 2 (April-May 2021) using the Warwick-Edinburgh Mental Well-Being Scale (WEMWBS; short version, Tennant et al., 2006). Higher scores on the WEMWBS indicate better well-being. The minimum score is 14 and the maximum score is 70.

- At Wave 1, the average score on the WEMWBS was 20.38. At Wave 2, the average score was 20.96.

### **What would make the lives of carers better?**

- Family carers and paid support staff of people with learning disabilities in Cohort 2 at Wave 2 were asked what would make their life as a carer better right now.
  - The most common responses to this question were about the need for a break, a holiday, the recommencement of day services, and/or respite.
  - Carers also wrote about their desire for the easing of restrictions, with many describing that this would allow them, and the person with learning disability who they care for, to meet with their family and friends.
  - For family carers who did not live with the person they cared for, they particularly emphasised a desire to have close contact and to be able to do activities together.

### **What happens next?**

The Wave 3 interviews and surveys will be starting in July 2021 for people who took part in the Wave 1 and/or interviews and surveys.

This research was funded by UK Research and Innovation (Medical Research Council), and supported by the Department for Health and Social Care (National Institute for Health Research) as part of the UKRI-DHSC COVID-19 Rapid Response Rolling Call.

This document contains the results from independent research funded by the Department for Health and Social Care (DHSC) (National Institute for Health Research; NIHR) and UK Research and Innovation (UKRI) (Medical Research Council; MRC). The views expressed in this document are those of the author(s) and not necessarily those of DHSC, NIHR, UKRI or MRC.

## Research team contact details

### England

Sue Caton:

Email: [s.caton@mmu.ac.uk](mailto:s.caton@mmu.ac.uk)

Telephone: 07425 374068



### Northern Ireland

Peter Mulhall:

Email: [p.mulhall@ulster.ac.uk](mailto:p.mulhall@ulster.ac.uk)

Telephone: 028 90366318



### Scotland

Roseann Maguire:

Email: [Roseann.Maguire@glasgow.ac.uk](mailto:Roseann.Maguire@glasgow.ac.uk)

Telephone: 0141 211 3902



### Wales

Edward Oloidi:

Email: [edward.oloidi@southwales.ac.uk](mailto:edward.oloidi@southwales.ac.uk)

Telephone: 01443 483 042

