



Coronavirus and People with Learning Disabilities Study

Wave 1 Results - March 2021

Highlights from the Full Report

Background

- This study is designed to systematically and responsively track the experiences of adults with learning disabilities through the COVID-19 pandemic over time across the four UK nations.
- There will be three 'Waves' of data collection over a 12-month period. Wave 1 data were collected between December 2020 and February 2021.
- There are two 'Cohorts' of participants in this study.
 - In Cohort 1, 621 adults with learning disabilities were interviewed by researchers
 - In Cohort 2, 378 family carers or paid support staff took part in an online survey about the experiences of the adult with learning disabilities who they supported/cared for. These were likely to be adults with more severe to profound learning disabilities. In Cohort 2, 166 of the adults were described as having profound and multiple learning disabilities (PMLD)
- This document presents the highlights from the full report of the Wave 1 results, published in March 2021. You can download the full report [here](#). You can download the Easy Read highlights [here](#).

COVID-19 infections and deaths, shielding and health

- 3% of people with learning disabilities in Cohort 1 and 7% of people with learning disabilities in Cohort 2 had received a positive COVID-19 test since March 2020. For comparison, the total cumulative prevalence of people in the UK who had tested positive for COVID-19 by 28th February 2021 was 6%.

- A further 5% of people with learning disabilities in Cohort 1 and 3% of people with learning disabilities in Cohort 2 thought (or their carers thought, in the case of Cohort 2) that they had had COVID-19, but this had not been confirmed by a COVID-19 test.
- Of those who had, or thought they had, COVID-19 16% of people with learning disabilities in Cohort 1 and 14% in Cohort 2 were hospitalised because of their COVID-19 symptoms.
- 16% of people with learning disabilities in Cohort 1 and 8% in Cohort 2 had someone close to them die due to COVID-19.
- 51% (Cohort 1) and 67% (Cohort 2) of people with learning disabilities had health conditions that were of concern if they had COVID-19. The most common health conditions were asthma and epilepsy.
- 31% (Cohort 1) and 58% (Cohort 2) of people with learning disabilities had shielded at some point since March 2020. In Cohort 2, 30% of those shielding were not formally told to shield, but still felt that they needed to.
- In Cohort 2, 30% of family carers/paid support staff said the physical health of the person they support had changed for the worse since the first national lockdown in March 2020.

Worries about COVID-19

- More people with learning disabilities in Cohort 1 were concerned about their family or friends catching COVID-19 (80%) than were worried about catching it themselves (66%).
- 50% of people with learning disabilities in Cohort 1 were at least a little worried to leave the house.
- People with learning disabilities in Cohort 1 were generally happy or accepting about their family or carers wearing PPE, acknowledging that it was necessary to keep everyone safe.

COVID-19 vaccine

- The vast majority of participants in both cohorts (>80%) indicated that they, or the person they supported/cared for, would take the COVID-19 vaccine if it were offered to them.

The impact on access to health and social care support

- Over 60% of people with learning disabilities in Cohorts 1 and 2 who had routinely seen healthcare professionals before the first lockdown in March 2020 had seen them less or not at all since then.
- As many as 23% of people with learning disabilities in Cohort 1 and as many as 41% of people with learning disabilities in Cohort 2 had a medical test or a hospital appointment cancelled since the first lockdown in March 2020.

- Of the 46 people with learning disabilities in Cohort 2 who had been admitted to hospital for a reason unrelated to COVID-19, 82% were allowed to have a carer stay with them during their admission.
- 46% (Cohort 1) and 48% (Cohort 2) of people with learning disabilities who usually have an annual health check, had not had one since the first national lockdown in March 2020.
- Of those who regularly used these services before the first lockdown, 99% of participants in Cohort 1 reported community activities had stopped completely or reduced by the time of the interviews, and 89% reported their day service had stopped completely or reduced.
- Carers of people with learning disabilities in Cohort 2 regularly using these services before the first lockdown reported that 95% of people with learning disabilities had experienced short breaks/respite stopping or reducing, whilst 98% reported day services stopping or reducing.

The impact on wellbeing and employment

- In Cohort 1, over 65% of people with learning disabilities had felt angry or frustrated, sad or down, and worried or anxious at least some of the time in the four weeks before their interview.
- Over 60% of participants in Cohort 2 reported that the person they support/care for had worse well-being since the start of the first lockdown in March 2020
- Over 85% of people with learning disabilities in Cohort 2 had some form of visitor restrictions where they lived.
- Over 65% of people with learning disabilities in Cohort 2, with and without PMLD, were reported to have experienced a negative impact as a result of visitor restrictions, and this was particularly the case for people with PMLD (74%) compared to people without PMLD (63%).
- Carers in the Cohort 2 survey reported that their health had been affected by their caring role in the last 4 weeks, most commonly disturbed sleep (57%), feeling tired (64%) and feeling stressed (65%).
- Of the 32% of people with learning disabilities in Cohort 1 who had a job before the March 2020 lockdown, 88% were still in employment (still working, furloughed, or with their job held for them).
- Of the 50% of people with learning disabilities in Cohort 1 who did volunteer work before the March 2020 lockdown, 81% had kept their volunteer role during this wave of the study, even if they were not currently working.

Contact with friends and family and help from family

- 72% of people with learning disabilities in Cohort 1 reported that they were staying in touch with important people in their lives as much as they wanted.
- 92% of people with learning disabilities in Cohort 1 used the internet at home.

- In both cohorts, participants were most commonly getting help with food shopping from their family members (40% Cohort 1, 56% Cohort 2).
- In both cohorts, people with learning disabilities most commonly got help from family to get their medicines (25% Cohort 1, 53% Cohort 2).
- Only 1% of people with learning disabilities in both cohorts were finding it difficult to access food or medicines.
- 12% of people with learning disabilities in Cohort 1 were caring for someone they were living with.

What happens next?

The Wave 2 interviews and surveys will be starting in late March 2021 for people who took part in the Wave 1 interviews and surveys.

We are still hoping a few new people will join the study. Please get in touch with the research team, using the contact details below, if you are:

- A person with learning disabilities who is from an ethnic minority background
- Supporting a person with learning disabilities who is from an ethnic minority background and who would not be able to take part in an interview with a researcher themselves, or
- Supporting a person with learning disabilities who does not live in their family home and who would not be able to take part in an interview with a researcher themselves.

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