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COVID-19 and People with Profound Multiple Learning Disabilities: What did people tell us at Wave 4 (September to December 2022)?

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

Our Coronavirus and People with Learning Disabilities Study has been collecting data from people with learning disabilities and family carers/support workers since 2020. The team wanted to make sure that the experiences of people with learning disabilities were visible during the pandemic. We have been collecting data from people with learning disabilities who were able to take part in an interview (cohort 1) and from family carers and support workers for people unable to take part in an interview themselves (cohort 2). Cohort 2 included people with Profound and Multiple Learning Disabilities.

Family carers, support workers and organisations who work to support people with Profound and Multiple Learning Disabilities, including PMLD Link, have worked with us to help us to ask the right questions. The research has focused on three key areas:

- 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?
- What actionable factors are associated with better outcomes for different groups of people with learning disabilities?
- What urgent issues concerning people with learning disabilities are emerging over time?

This article is a summary of the information about People with Profound and Multiple Learning Disabilities. The data on which this article is based was collected between September and December 2022, Wave 4. You can read the full reports here: coronavirus_and_people_with_learning_disabilities_study_wave_4_full_report_final.pdf (warwick.ac.uk).

Who did we collect information on?

In Wave 4, eighty six family carers or support workers who completed the survey told us that they were answering about someone identified as having Profound and Multiple Learning Disabilities. People were living in all four nations of the UK. They mostly lived at home with family (66%). The mean age of the person with a Profound and Multiple Learning Disability was 33 years (16-73 years). Just over half of the group were male (56%) and 92% had been identified as being White British.

What were key issues?

COVID-19

Most people with Profound and Multiple Learning Disabilities (71%) were reported to have had COVID-19 and to have had COVID-19 vaccines (74%). Over a third of people with Profound and Multiple Learning Disabilities were reported to be still testing for COVID-19. Whilst the majority of the UK population were no longer taking any action regarding COVID-19, most people with Profound and Multiple Learning Disabilities were reported to be doing at least something to keep themselves safe from COVID-19. This included shielding, staying away from groups and continued use of PPE.

Figure 1 here

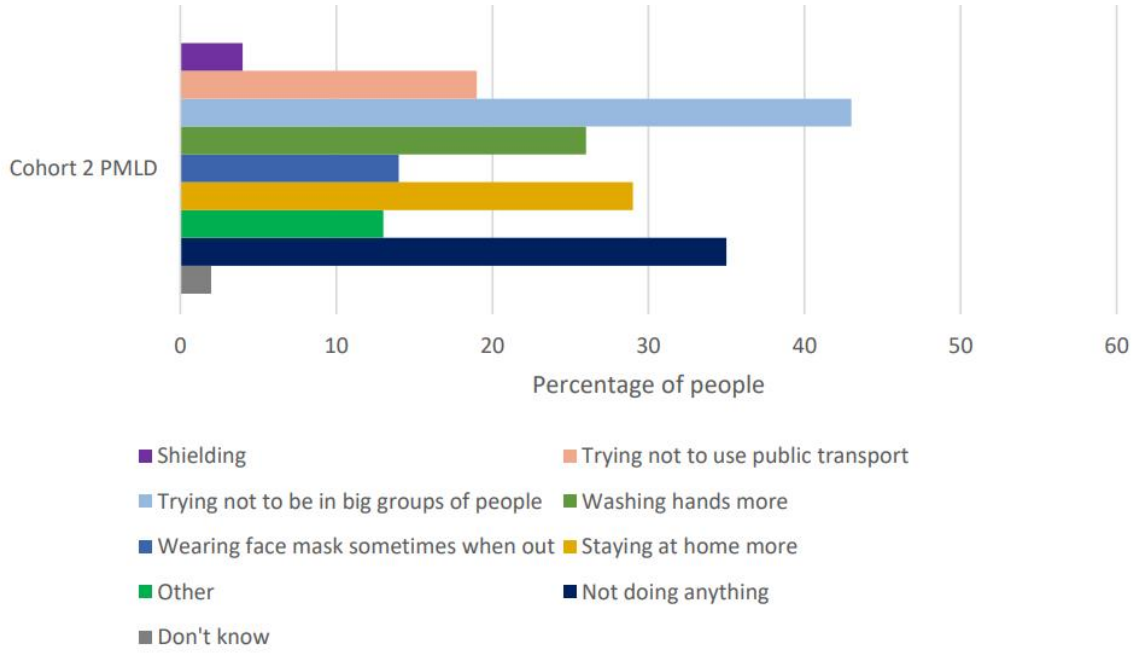


Figure 1 .1. What people with Profound Multiple Learning Disabilities are reported to be doing to keep themselves safe from COVID-19 (tick all that apply)

Physical and Mental Health

By the end of 2022, around one third of people with Profound and Multiple Learning Disabilities (35%) were reported to have had a new health condition and/or an existing health condition that was getting worse in the four weeks before the survey. The health of people with Profound and Multiple Learning Disabilities was reported to be worse at Wave 4 than at any of the previous waves. At Wave 4, 28% of people with Profound and Multiple Learning Disabilities were waiting for a medical test and 65% of people had NOT had an annual health check since Jan 2022.

Like the general population, COVID-19 impacted people's mental health and wellbeing. We asked questions about whether people were feeling angry or frustrated, sad or down and worried or anxious. Whilst everyone in Cohort 2 who was not identified as having Profound and Multiple Learning Disabilities were generally reported to have felt less angry or frustrated, sad or down and worried or anxious over time, there was a different trend for people with Profound and Multiple Learning Disabilities. More people with Profound and Multiple Learning Disabilities were reported to be feeling angry or frustrated over time. More of this group were also reported to be feeling worried or anxious at the end of 2022 than was reported in Wave 3 (July to August 2021).

Support

Most people with Profound and Multiple Learning Disabilities (86%) were seeing family at least weekly by Wave 4. For those people with Profound and Multiple Learning Disabilities who were living in housing organised by services (34%), at least some form of visitor restrictions were reported to be in place for 29% of people.

At Wave 1 (December 2020 to February 2021), it was reported that 69% of people with Profound and Multiple Learning Disabilities used to regularly go to a day service before the pandemic. At Wave 4, 46% of people with Profound and Multiple Learning Disabilities were reported to have been

to a day service in the last 4 weeks. In terms of community activities, the figures were 78% and 47% respectively. Personal assistant/support workers helping at home was also still lower at Wave 4 (62%) than reported at Wave 1 (71%).

Fewer people with Profound and Multiple Learning Disabilities left the house for almost any reason compared to other people with learning disabilities at Wave 4. At Wave 1, 78% of this group reported regularly going out of the house with paid support before the pandemic. At Wave 4, only just over half of people with Profound and Multiple Learning Disabilities (55%) were reported to have been out of the house with people who were paid to support them in the last four weeks. Although increasing over time, fewer people with Profound and Multiple Learning Disabilities were going to a short break or respite service (24%) in the last 4 weeks at Wave 4. At Wave 1, nearly half of people with Profound and Multiple Learning Disabilities (46%) were reported to be regularly using these services.

Family carers of people with Profound and Multiple Learning Disabilities

The self-reported general health of family carers of people with Profound and Multiple Learning Disabilities generally got worse from Wave 1 to Wave 4, with 48% of family carers of people with Profound and Multiple Learning Disabilities rating their health as fair or poor at Wave 4, compared to 38% at Wave 1.

We asked family carers about the impact of their caring role on their health and wellbeing. By Wave 4, reports of impact of their caring role on their health of feeling tired, stressed and disturbed sleep had increased in comparison to reports at Wave 1. By Wave 4, 94% of family carers of people with Profound and Multiple Learning Disabilities reported that at least one of the listed impacts of their caring role on their health applied to them.

Family carers and support workers of people with Profound and Multiple Learning Disabilities were asked when they thought that life might return to normal. Nearly a third of respondents (32%) thought that life for this group would never return to normal.

Reflections

It is apparent that the impact of the COVID-19 pandemic was still being felt by people with Profound and Multiple Learning Disabilities and their family carers by the end of 2022. Most people with Profound and Multiple Learning Disabilities were not accessing services and community activities as much as they were previously. People with Profound and Multiple Learning Disabilities and those who supported and cared for them were still making adaptations to their lives to protect themselves and others from COVID-19. The physical health and wellbeing of People with Profound and Multiple Learning Disabilities were reported to be worse over time. Support and services had not returned to pre-pandemic levels in many areas. Almost all family carers reported that their caring role had impacted on their health.

In previous Waves, carers highlighted the need to prioritise the protection of existing skills of people with Profound and Multiple Learning Disabilities. We also identified three areas regarding what would make life better for people with Profound and Multiple Learning Disabilities (Bradshaw et al, in submission). Carers suggested that they needed better access to health and social care, increased opportunities for social contact and activities and to be supported by consistent, responsive staff. In general, across all of the questions we asked at Wave 4, things were less positive for those people who had greater support needs and these differences have been increasing over time. We need to continue to highlight these inequalities and to prioritise the health and wellbeing of both People with Profound and Multiple Learning Disabilities and those who care for them.