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Coronavirus and people with learning disabilities study: What we found out about People with PMLD

Jill Bradshaw, Amanda Gillooly and the Coronavirus and people with learning disabilities study team

Wave three of our study took place in July and August 2021. Surveys were completed by 118 family carers and paid supporters of people with PMLD.

- Nearly everyone (88%) said that they thought there should still be restrictions like wearing face masks and social distancing (PPE)
- In the last 4 weeks before completing the survey, 38% of people with PMLD were reported to have had a test for COVID-19. Common reasons for a test were that everyone where they lived were tested (27%) or being asked to do a test before going to the day centre (9%)
- Fourteen percent of family carers or paid supporters thought that the person with PMLD they cared for had had Covid-19. Five of these people (31%) were hospitalised because of their COVID-19 symptoms.
- Twenty two percent of people with PMLD were shielding.
- Most family carers/paid support staff (54%) of people with PMLD reported wearing PPE.
- Thirty four percent of people with PMLD had been wearing face masks/coverings when they were going out in the week before survey completion.
- Nearly everyone (95%) with PMLD had received at least one COVID-19 vaccine and 93% had received two doses and most people (93%) were reported to be likely to accept a booster when offered.
- Most family carers/paid support staff of people with PMLD (83%) told us that they thought that paid support staff and personal assistants should have to have the COVID-19 vaccination.
- When asked about their general health today, family carers/paid support staff of people with PMLD most commonly rated the health of the person they supported/cared for as good. Almost a third (30%) of people with PMLD were reported to have had a new or worsening health conditions in the last four weeks.
- Most family carers/paid support staff of people with PMLD reported that the person they support/care for had felt worried or anxious (69%), sad or down (68%) and angry or frustrated (80%) at least some of the time in the last four weeks.
- Over 40% of people with PMLD had been waiting for a test, operation or outpatient hospital appointment for more than six months.
- Just over a quarter of people with PMLD (26%) had had an annual health check since the start of the year (2021), with around half of these checks being done by phone or video link.
- For people with PMLD, the most frequently reported ways of staying in contact with family and friends were meeting face-to-face (72%), meeting outside (61%) and meeting in the person's own house (54%).
- Three quarters of people with PMLD who were not living with family had restrictions on visiting their home imposed by services (75%). The majority of these (58%) were reported to have experienced a negative impact as a result of visitor restrictions.
- Only 12% of people with PMLD had returned to everywhere they used to go before the pandemic.
- Fifty six percent of people with PMLD were reported to be getting less support now compared to before the COVID-19 pandemic.

- Nearly half (47%) of people with PMLD were reported to be using money for services not currently being received.

All the findings from the project are free to access from

<https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability> (including the full report of the findings from the 3rd wave of the study)