



September 2023

The Coronavirus and People with Learning Disabilities Study

Pandemic Stories



This report is about the Coronavirus and People with Learning Disabilities Study research.



It has been over 3 years since the coronavirus pandemic started.



We wanted to hear more about how life has been for people with learning disabilities and what life is like now.



This report is about what people told us.

What we did

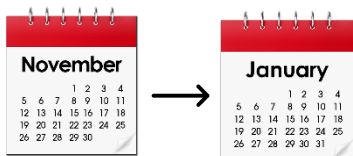


We interviewed 8 people with learning disabilities who live in England.

We also interviewed 6 family members of people with profound and multiple learning disabilities (sometimes called PMLD).



We interviewed everyone online two times so that everyone had enough time to tell us their story of living through the pandemic.



We interviewed people between November 2022 and January 2023.

What we found

What people with learning disabilities told us



There were **3** things that the stories people with learning disabilities told us had in common.

1

Living in supported living or residential care could be scary.



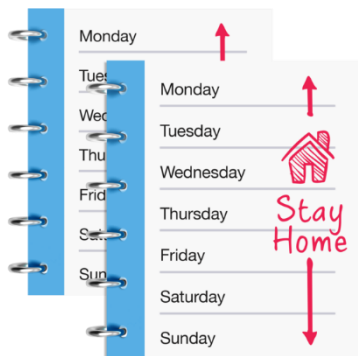
People were worried about coronavirus being easy to catch in places where a lot of people live together.



Sometimes it was difficult for everybody to keep their distance.



People living in care homes had a very difficult time.



People living in care homes had to follow extra rules. They were not allowed to leave their home for a very long time.



People living in care homes had housemates who died from Coronavirus.

2

The pandemic stopped people from doing things that are important to them. Families, charities, and self-advocacy groups helped people.



Not having things to do was bad for people's mental and physical health.



People felt frustrated.

People felt like they had lost their independence.



Families, charities, and self-advocacy groups gave people things to do like Zoom calls or activities.



Families, charities, and self-advocacy groups also gave people emotional support.



The support that people get from their families, charities, and work is still really important to people.

3

People feel angry and worried.



Some people said they felt angry about how the government acted during the pandemic.



If another pandemic happened, people hoped that the government would support people with learning disabilities better.



Some people are still having problems getting the support and housing that they need.



People are worried about the cost of living crisis and are worried about not having enough money.

What family members of people with profound and multiple learning disabilities told us



The stories family members of people with PMLD told us had **4** things in common.

1

Unfair lives got worse.



People told us that they thought the Government and local services did not think about them enough during the pandemic.



They felt abandoned.



People said it was very hard to get healthcare and support during the pandemic.



It is still difficult now.



People said there are not enough paid carers now.





Not being able to get support was having a bad effect on the person with PMLD's wellbeing and health.



Some people with PMLD are still trying to be safe from coronavirus.

2

People's daily lives and relationships changed.



People said their family members with PMLD found the pandemic rules very hard to understand.

They did not always understand why they could not see their families.

People could not go home. They missed hugs from their family members.

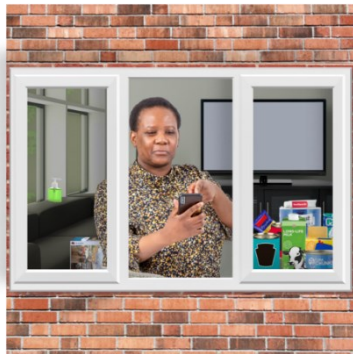


This made people sad and anxious. It sometimes led to behaviour that challenges and poor mental health.



The pandemic was bad for some relationships between people with PMLD and their family members.

Families said that some relationships were still not better.



Even when the rules to stay at home ended, some people were not going out as much as before.



Some families said that communication with care homes or supported living settings was not very good during the pandemic.

For some families, communication was still poor.



Some people were proud of how well their family member with PMLD coped with such a big change in their lives.

3

People were worried about the future for their family member with PMLD.



Many people worried about what would happen to their family member as they got older and were unable to care for them.



The pandemic made these worries worse because it made a lot of people think about dying.

4

The pandemic made family members of people with PMLD very tired.



Our interviews were about the stories of people with PMLD, but their family members also told us about their own lives.



Having less support was stressful. Not seeing family members for a long time was very upsetting.



Some people said they still hadn't recovered and were very tired.

If you want more information or have any questions, please contact:



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