



Frequently Asked Questions

Thank you for your questions and comments. We have focussed on questions which summarise a key theme from stakeholders. If you do not think we have answered your question, or if we have missed anything, please do come back to us at: england.learning.disability@nhs.net

All webinar materials will be uploaded to the Future NHS Collaboration workspace. We use this platform to share resources; if you currently have a FutureNHS account, you can access the workspace directly through the homepage (<https://future.nhs.uk/MHLDAcovid19/grouphome>). Those without a FutureNHS account can either self-register to the platform if they have an nhs.net or nhs.uk email account, or directly request access by emailing our generic mailbox if they are from other organisations at: MHLDAcovid19-manager@future.nhs.uk.

Key topics this week:

- **Question and answer from research presentations:**
 - **The impact of COVID-19 on autistic people, in the United Kingdom, Martin Knapp and Sarah Pais**
 - **Coronavirus and people with learning disabilities, Chris Hatton and Richard Hastings**
- **Published resources**

Updates from the Department of Health and Social Care:

- Question and answer from research presentation

Please note that the following responses are directly from the researchers, not from the Department of Health and Social Care

1. *Question from webinar:* Will more in-depth information of the research be available e.g. stats?

Answer from researcher Martin Knapp: The full report will be published alongside the new Autism Strategy in due course. The report is a distillation of findings from other people's research, and so we do not have in-depth statistical analyses in our work.

2. *Question from webinar:* Please could you provide a reasoning for why you made those recommendations?

Answer from researcher Martin Knapp: The recommendations flow out of the findings that we got from our review of other people's research and from our

discussions with people with lived experience and other stakeholders. The recommendations are generally at a high level of generality, with more detail given in the report on some of them.

3. *Question from webinar: Can you share if there have been any positive outcomes for autistic people during the pandemic from your research - for example - what has been the experience for people with autism in remote consulting?*

Answer from researcher Martin Knapp: There have been some positive experiences. For example, some children who were anxious about attending school found lockdown to be a bit of a relief. Some were less stressed at home because they were away from bullies and the experience of being left out of friendship groups. Not having to wear school uniform and having breaks when needed were also positives. Some schools were very supportive, and some (including special schools) continued to operate during lockdown, but some schools had no contact with autistic pupils during lockdown. When therapeutic support continued and support from school was comprehensive, families reported benefits. For some autistic pupils, home-schooling arrangements worked very well, but again experiences were highly variable, and many parents of children with special educational needs found it particularly challenging to educate their child at home.

Lockdown provided an environment where people had 'freedom to deviate from society's expectations', not having to conform to societal norms. They could work at their own pace doing daily activities, and many appreciated this slower way of life.

Many families reported reduced anxiety/stress because they faced less evident stigma and discrimination during lockdown (because of the reduced time spent in public).

Another positive experience was reported by a large service provider: the restrictions introduced in lockdown (including reduced choices available in relation to activities and less opportunity to venture outside) appeared to lead to reduction in challenging/distressing behaviour and in stress/anxiety for some autistic people. It was reported that there was greater continuity in staff support because of fewer staffing changes (necessitated by infection control restrictions), meaning that there were smaller staff teams and no/little leave for staff during the period of lockdown. Of course, these are not sustainable benefits.

Some adult autistic people enjoyed the opportunity to work remotely and using new technologies: they comfortable working online and were already utilising technology to manage other parts of their lives before lockdown. Better understanding and support from employers helped parents to look after their autistic children at home, although the extent and nature of this support varied considerably between employers.

4. *Question from webinar: Do we have any specific details of COVID-19 deaths for people with autism, and similarly do we have details of excess deaths or morbidity e.g. missed malignancies?*

Answer from researcher Martin Knapp: The data on COVID-19 deaths come from figures compiled by the Office for National Statistics (ONS). Thus far, those statistics

have not specifically identified autistic people. In our report we refer to the findings that people with learning disabilities have much higher mortality rates than the general population, and we note that some people with learning disabilities are autistic. However, we did not find any evidence to say whether autistic people specifically have higher mortality rates. Our understanding is that future collections of data by ONS will separately identify autistic people.

5. *Question from webinar: Please can you clarify if you were making those recommendations because you were saying those things had happened well, or that those things should have happened*

Answer from researcher Martin Knapp: The recommendations were suggesting what could be done to improve the situation for autistic people in terms of their health, wellbeing, and various other domains.

6. *Question from webinar: Within the population of people who had a learning disability, did the study separately identify those who had been added to the Clinically Extremely Vulnerable list*

Answer from researcher Martin Knapp: As noted, our study was – generally – summarising findings from the sometimes very detailed work by others. We did not find evidence on autistic people who had been added to the Clinically Extremely Vulnerable list.

7. *Question from webinar: From your research do people feel their voice is heard when consulting digitally or does the discussion become carer dominated?*

Answer from researcher Chris Hatton: In the interviews with adults with learning disabilities, in 62% of the interviews people completed the interview without any help (many people lived alone or with a partner) and in a further 7% of interviews someone was present but the person answered the questions without help. 16% of people had help from a member of staff, 13% had help from someone who lived with them and 2% had help from someone who did not live with them. Interview teams have not raised carers dominating the conversation as an issue – in some ways conducting the interviews remotely mean that people are more in control of when the interviews happen and who, if anyone, they want to be present.

8. *Question from webinar: Did people comment on using Patient Initiated Follow Up's (PIFUs)?*

Answer from researcher Chris Hatton: We did not explicitly ask about these. The questions in Wave 1 (as in other COVID-19 experience surveys) were more about health services and health appointments being cancelled or reduced since the start of the first lockdown.

Published resources:

- DHSC release: [Mental health recovery plan backed by £500 million](#)

- [Disability charities benefit from £2.4 million fund - GOV.UK \(www.gov.uk\)](https://www.gov.uk)
- **Podcast: Vaccinating people with a learning disability and autistic people:** NHS England and NHS Improvement, Learning Disability and Autism, National Clinical Director in conversation with Fazilla Amide, whose 17 year old son has complex health needs, learning disability and autism. They talk about the importance of collaborative working across health and social care to ensure the best outcomes can be achieved for people with a learning disability and autistic people in vaccination appointments. The podcast provides advice and support around good communication, the range of reasonable adjustments that should be considered and issues around anxiety and needle phobia. As well as providing some specific examples of good practice. <https://soundcloud.com/nhsengland/vaccinating-people-with-a-learning-disability-and-autistic-people/s-YYIN8wqAFgd>

Vaccine good practice

We have been collecting stories to share about people with a learning disability and autistic people getting the coronavirus vaccine. If you have examples of great support for people to get their vaccines (reasonable adjustments) or stories that will encourage other people to get the vaccines, please let us know.

[Vaccine in a carpark in Great Yarmouth](#)

[Giving vaccines in a quieter place in Liverpool](#)

[Letting people know what it's like before the appointment- Devon](#)

[In the Wirral, supporting Amanda, who has a learning disability, overcome her fear of needles](#)

[Working with parent carers to make reasonable adjustments for people with a learning disability in Shropshire](#)

[Superhero efforts in Leicester](#)

People's vaccination stories and tips

[Tony gives tips about getting the vaccine for autistic people](#)

[Ciara, from Mencap, talks about getting her vaccine](#)

[Emily, from Skills for People, talks about getting the vaccine](#)

[James, from Ace Anglia, shares his vaccine story and talks about side effects](#)

[Jemma, from Ace Anglia shares her vaccine story](#)

[Self advocates from the North West Training and Development Team talk about getting the vaccine](#)

[Shamima, who has a learning disability, and Yasmin talk about getting vaccine](#)

Future webinars

The next webinar will be on 14 April. If there is a specific theme you would like to discuss or present please let us know.

Additional information

For Public Health England weekly updates sign up here:

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