

Spotlight Report:

Learning Disability and Autism - Covid-19 Survey

Healthwatch Worcestershire developed a survey to gather experiences of people with a learning disability and Autism during the Coronavirus outbreak. This report contains an overview of responses in the first four weeks of running the survey, to give timely feedback to local health and care services.

Between 14th May and 15th June 36 people completed the survey.

- 13 people answered the survey questions by phone. Questions were asked by SpeakEasy N.O.W. as part of contact they have been having with people with a learning disability, many of whom do not have online access or would find it difficult to engage online.
- 12 people completed Easy Read paper copies of the survey. These were posted to people who said they would find this easier than completing the survey online.
- 11 people completed the survey online

We also spoke to 6 people with a learning disability via Zoom as part of a SpeakEasy N.O.W. Health Checkers meeting.

Who completed the survey?

- 16 people who live with family, 13 people who live independently and 7 people in supported living
- 33 have a learning disability, 9 have Autism and 10 have additional medical conditions
- There were responses across all age categories from 18 to 64 and across all districts in Worcestershire, with highest number from Wyre Forest (9) and lowest from Malvern Hills (2)

Information

Most people told us they had been able to get information about Coronavirus and how to keep safe. But only about half said that they were definitely able to get information that is easy to understand.

When asked what information had been helpful, the most popular responses relating to type of information were Easy Read or easy to understand information and information received from SpeakEasy N.O.W. Other sources of information given were television, radio, leaflets, NHS website, care agency and parents explaining things. Although two people mentioned they found the news and television confusing.

'I don't understand what they talk about on the news'

The most common topic for information people had found useful was explaining current guidelines, including how to stay safe, what you can and can't do, social distancing and hand washing.

'Helps me to understand why I have to stay at home and cannot see my mum.'

Other useful types of information mentioned included symptoms of Coronavirus, what to do if you are ill and opening times of the shops.

When asked what other information people would find helpful, the most common response was information about current guidance.

'What you can and can't do. I find it very confusing'

Easy Read information, information about specific impact and symptoms for people with a learning disability, testing for Coronavirus and information sent by post due to not having a phone or computer were also mentioned.

Health Services

We asked what experiences people have had of accessing health services during the Coronavirus outbreak.

13 people told us about the contact they have had with their GP practice. 5 people told us about having appointments with the Doctor by phone or video call. Some thought this was a good idea.

'I had a telephone consultation. It lasted about 10 minutes. I found it funny at first and it took me a few minutes to get used to it.'

However, one person commented that it was not very helpful. When talking to SpeakEasy members some said that they would find it more difficult to talk to someone by phone or video call and that this might mean a support worker or carer having to do most of the talking for them. Therefore limiting opportunities for privacy and confidentiality.

Some people told us about going to the GP practice and how this was different.

'It was a bit scary because they all wore face masks'

We were also told about a GP calling every month to check someone was ok, receiving support from Community Nurse to attend GP appointment and changes to medication so that someone did not need to go to the GP practice for an injection.

8 people told us they had needed to get medication and mostly this had been ok. One had experienced long waits, one was unable to get medication required and one mentioned having support to order medication online.

4 people told us about experiences of going to hospital and how this was different, such as staff wearing masks and social distancing.

Other comments about health services included those that have been put on hold, including dentist and chiropody. One person said they have had toothache but not done anything about it.

Support

23 people told us there had been some (14) or a lot (9) of changes to the support they receive during the Coronavirus outbreak.

- 7 people told us that they had either moved back in with parents or had more support from parents during the outbreak.
- 4 people told us that they had found it difficult having different support workers.
- 2 people said they had received less support and it had not been when they wanted it.

Other comments about support included the impact of support groups being cancelled, impact of college closure, changes to shift patterns and procedures, impact on families of increased caring role, being worried about support workers getting ill and one person saying they are not currently receiving any support.

5 people made comments about having good support or their support continuing as usual. Including examples of how support has been especially important.

'My support help me to calm down as I get very anxious'

How people have been feeling

Most people (32) told us that Coronavirus and staying at home had made them feel a bit (23) or a lot (9) worried or sad. 18 people thought they definitely had someone they could talk to about this and nearly all of the other respondents said yes - kind of.

13 people told us about how they have been feeling worried or anxious.

'I get scared when I go out because it's so quiet and then when I see someone I worry they are going to infect me. I always move away if I can but sometimes you can't and we are too close.'

'Lockdown has been hard. The thought of having to wear masks in the future to go out is worrying me.'

'I get anxious at night and sometimes can't get to sleep. I'm better in the daytime when I can ring or text someone.'

'It makes me feel very anxious and I wish I lived with someone else.'

'I'm a bit scared about getting the virus. I don't want to have to go into hospital.'

6 people made comments about missing their friends, family and activities such as day service.

'I don't like having to stay away from my friends and I miss them.'

4 people told us how support workers and family had made them feel better or supported them to stay in touch with others. Other comments included video calls not being the same as seeing people and not having anyone to talk to.

As part of the discussion with members of SpeakEasy we talked about using video calls to keep in touch with people. Although they were all finding it helpful during lockdown, they were worried about not being able to see people face to face soon. They knew people with a learning disability who did not have any access to a computer or smart phone. They knew people who did have the technology but were having problems working it without someone being able to show them. Some people had support to use the technology, but needed to have a support worker or carer with them when they talked to others. Meaning they could not have a private conversation. They also thought that it is not always easy to talk about how you are feeling on a video call or for others to know if you are really ok.

Points for consideration based on responses to date -

- People with a learning disability and Autism may not have online access or be able to use technology to engage online, especially without support or carer present.
- Consideration of these issues when planning further use of telephone and video calls for health appointments.
- Importance of information about Coronavirus being available in easy to understand format and that people, especially those without online access, can access visual and written information.
- The need for information and support when visiting health services, to reduce anxieties and understand changes implemented.
- Reassurance that people are receiving allocated / required levels of support.
- Consideration about impact on family and carers of additional caring responsibilities.
- Consideration about how anxieties related to Coronavirus and changes to normal activities can be supported.
- Recognising importance of opportunities for people to meet up face to face and activities to restart to emotional wellbeing.
- Consideration about information and support available as people start going out more, to reduce anxieties and maintain independence.

In order to gather further feedback from people with a learning disability and Autism, under current restrictions, we would welcome support of Community Learning Disability teams and support providers to enable us to distribute paper copies of Easy Read surveys and ensure people have support required to complete the surveys.