

Covid-19

Learning Disability and Autism Report



September 2020



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Note - Copies of the survey and related Spotlight Report are available on our [website](#)

Covid-19: Learning Disability and Autism Report

1. Introduction

1.1 About Healthwatch Worcestershire

Healthwatch Worcestershire provides an independent voice for people who use publicly funded health and social care services. Our role is to ensure that people's views are listened to and fed back to services and commissioners in order to improve services.

1.2 Why this work?

The Covid-19 outbreak and resulting restrictions have had and continue to have an unprecedented impact on our everyday lives and the way in which we access health and care services and support. In April, Healthwatch Worcestershire launched a survey to gather the experiences of people in Worcestershire during the Covid-19 outbreak. In addition to the main survey we recognised the importance of gathering feedback from people with a learning disability and Autism, in an accessible way, to help to understand their experiences and identify any specific issues.

Understanding the specific issues and concerns for people with a learning disability and Autism is important due to known health inequalities. The 2019 Learning Disabilities Mortality Review found that people with a learning disability are more likely to experience ill health, have a shorter life expectancy and die from an avoidable medical cause of death than the general population. The NHS Long Term Plan, launched by NHS England in 2019 has learning disability and Autism as a key work area, aiming to reduce these health inequalities.

The National Autistic Society published a report in September 2020 based on feedback from over 4,000 people with Autism during June and July. They found that 9 out of 10 people with Autism worried about their mental health during lockdown, 85% said their anxiety levels got worse and they were 7 times more likely to experience chronic loneliness than the general population. Their findings suggested that the Covid-19 pandemic had increase the health inequalities which already existed.

1.3 Our work

In total 113 people with a learning disability and / or Autism gave us feedback about their experiences during Covid-19.

We developed a Learning Disability and Autism Covid-19 Survey, which was available as an Easy Read paper survey and as a words only online version. This asked about experiences of accessing information during the pandemic, accessing

health and support services and the impact that Covid-19 and resulting restrictions was having on their emotional wellbeing and daily lives.

Between 27th May and 28th August 84 people completed this survey.

How were responses collected?

Of the 84 responses to our Learning Disability and Autism Covid-19 Survey:

- 27 people completed paper copies of the Easy Read Survey, including those distributed to members of SpeakEasy N.O.W. self advocacy, and by Where Next, a work and social opportunities provider.
- 25 people answered the survey questions as part of Zoom catch up meetings with Our Way Self Advocacy.
- 13 people were asked the survey questions on the phone, by SpeakEasy N.O.W. as part of contact they have been having with their members, many of whom do not have online access or would find it difficult to engage online.
- 19 people completed the survey online, following promotion via Healthwatch Worcestershire news bulletins, Facebook, SpeakEasy Now, Our Way, Monday Nite Club, Worcestershire County Council Young Adults Team, Speech and Language Therapy team and National Autistic Society Companions Group.

In addition to the Learning Disability and Autism Covid-19 survey:

- 23 respondents to our main HWW Covid-19 survey told us they had a learning disability or Autism Spectrum Condition. Key issues from their feedback have been included in this report. Report of complete findings from this survey can be found on our [website](#).
- We also spoke to 6 people with a learning disability via Zoom as part of a SpeakEasy N.O.W. Health Checkers meeting.

A Spotlight Report containing initial findings from the survey up until 15th June was produced in order to provide timely feedback to health and social care service providers and commissioners.

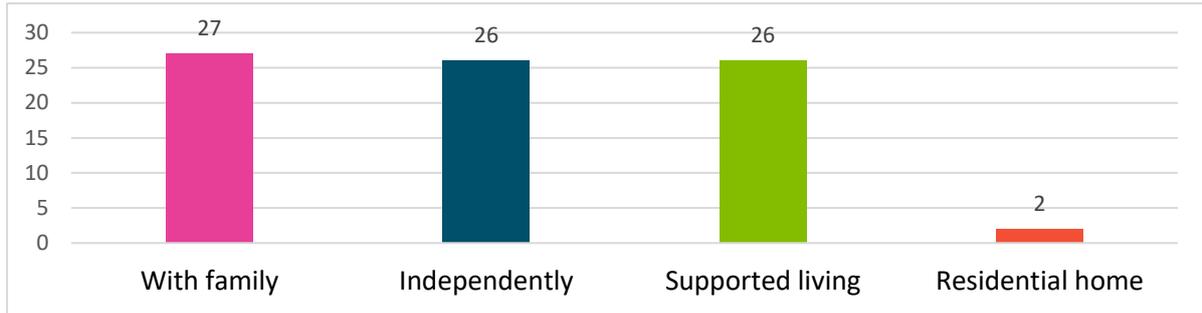
1.4 Who completed the Learning Disability and Autism Covid-19 Survey?

84 people completed the survey:

- 71 with a learning disability
- 27 with Autism

26 have additional medical conditions

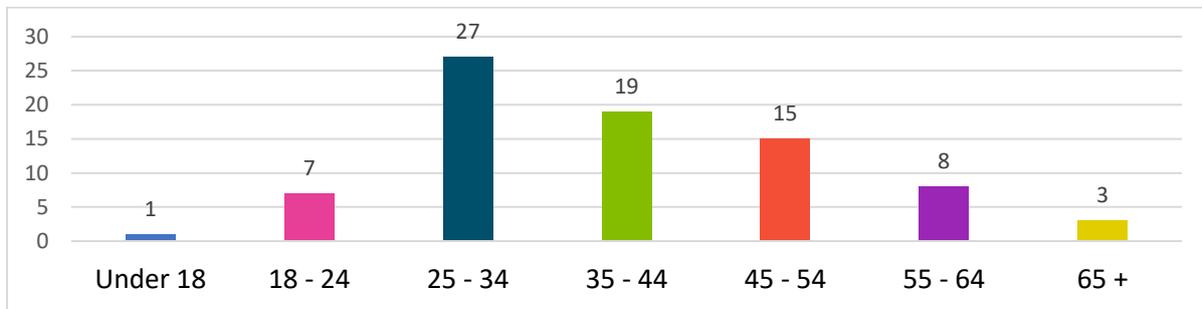
Who do they live with?



27 people live with family, 26 people live independently, 26 people are in supported living and 2 in residential care.

42 of respondents identify as female, 38 as male and 1 as other.

How old are they?



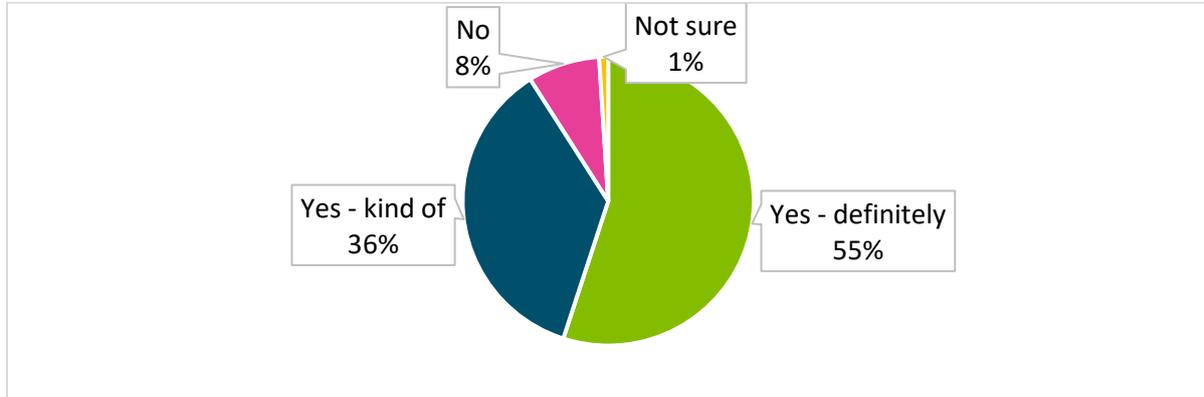
Where do they live?



There were responses across all age categories and across all districts in Worcestershire, with highest number from Wyre Forest (29) and lowest from Malvern Hills (7)

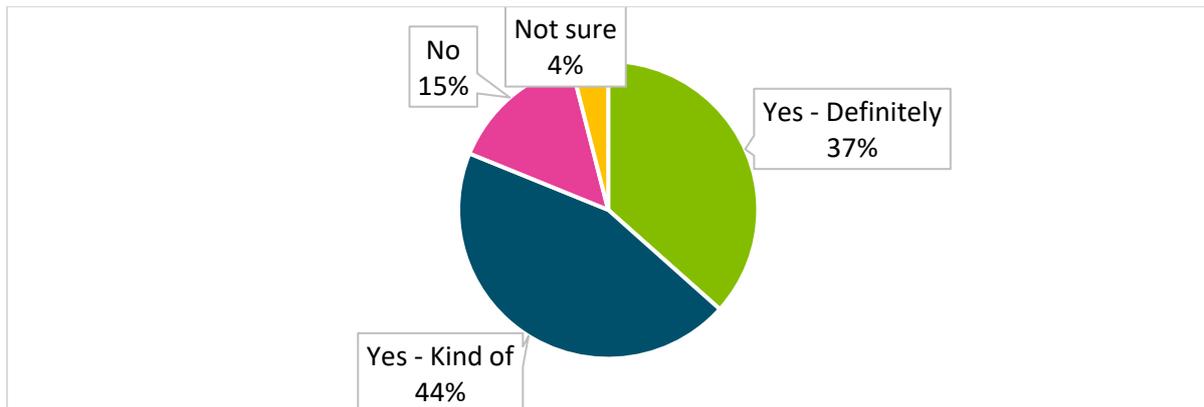
2. Information

2.1 Have you been able to get enough information about Coronavirus and how to keep safe?



Most people told us they had been able to get information about Coronavirus and how to keep safe.

2.2 Have you been able to find information that is easy to understand?



However, only 37% said that they were definitely able to get information that is easy to understand.

2.3 What information has been helpful?

Responses relating to the type or source of information:

- Support or care workers / organisation (13 people)
- TV / Prime Minister's briefings (13 people)
- Easy Read information (9 people)
- Family explaining (7 people)
- Information provided by SpeakEasy N.O.W. (5 people)

Other sources of information mentioned by one or two people were - Zoom sessions with Our Way, letter from the Prime Minister, Government messages, leaflets, online information, radio and the NHS website.

However, six people told us that nothing had been helpful and four people told us they had found television news confusing.

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

Responses relating to the topic of information:

- How to keep safe e.g. handwashing, PPE and social distancing (13 people)

'How to wear masks and gloves'

'To wash hands often. To remember to keep 2 meters distance and doing virtual hugs'

- Current guidance - what you can and can't do (6 people)

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

- Understanding Coronavirus (5 people)

'Being able to learn about the coronavirus and to understand it'

2.4 What other information would you find helpful?

13 people told us they wanted information about when restrictions could ease and they would be able to see friends and family and return to regular activities, such as work or voluntary work and there would not be a need for masks.

'When can I go back to work? When will things go back to normal?'

'When we can go back to hugging'

'I do not like wearing masks, when will this stop?'

12 people told us they would like information about current guidelines that was clear and easy to understand.

'More explanation about what you can and can't do when you go out and who you can see. I find it very confusing'

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

In our main Covid-19 survey three of the four people with Autism and or a learning disability who felt they had additional communication needs said they had not been able to find information in the format needed. One commented about the need for information and guidance to be clearer.

3. Health Services

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

3.1 GP Practices

26 comments gave feedback about their experiences of accessing their GP practice.

Positive comments (11)

- Praise for staff at GP practice, being kind and supportive (4 people)

'Everyone tried to be supportive and kind'

- Telephone and video call that have worked well (2 people)
- Feeling reassured by use of PPE and other infection control (2 people)

'Strict infection control and PPE guidance found this to ease the worry'

- Monthly check from GP practice to discuss wellbeing (1 person)
- Shorter waiting times when attending practice (1 person)
- Annual Health Check had been carried out by phone (1 person)

Issues / concerns (15)

- Contact and visiting the Doctor feeling different / making them feel anxious (8 people)

'I have had to attend lots of doctors appointments which I have found stressful as I worry that I am going to catch the virus'

'It was a bit scary because they all wore face masks and I had to wait a long time to be seen'

- Finding telephone or video consultations difficult (3 people)

'Had a telephone consultation which was difficult as I had to explain my condition. Wasn't sure if I was giving the correct information'

'XX from XX spoke on my behalf. It's easier for me face to face, have trouble on the phone and explaining'

- Needing support to be able to go to appointment, order medication and explain to the Doctor (3 people)
- Lack of Diabetes check / ongoing support for Diabetes (2 people)
- Not being able to see a Doctor face-to-face (1 person)
- Monthly visits stopped and treatment changed (1 person)

Some of the SpeakEasy N.O.W. members we spoke to told us they would find it more difficult to talk to someone by phone or video call. They thought that this might mean a support worker or carer having to do most of the talking for them, rather than talking to the Doctor themselves and this would mean it would be more difficult to have a private conversation.

3.2 Pharmacy

13 people told us they had needed to get repeat medication and this had mostly worked well. Although two people were unhappy about having to queue, one person was unable to get medication required and one told us about having support to order medication online.

3.3 Hospital

7 people told us about experiences of going to hospital and how this was different, such as staff wearing masks and social distancing in waiting areas. Most said this had made them feel safer. One person told us they had to stay on a ward with Covid-19 patients although they did not have Covid.

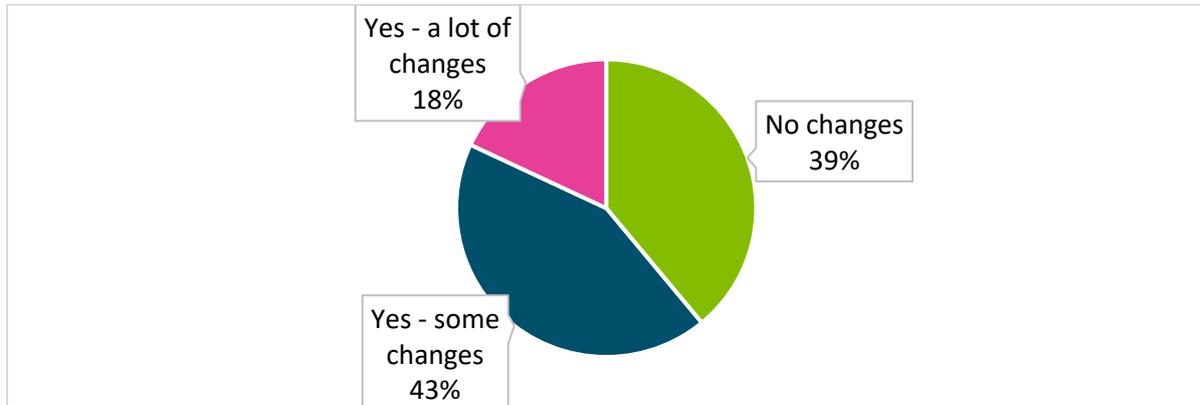
'Hospital totally different with great explaining of Covid guidelines'

3.4 Other health services

Other comments about health services included those that have been put on hold, including dentist, audiology and chiropody. Three people told us they had needed dental treatment but not been able to access it. One person told us they had been to the Dentist but their support was not able to come into the appointment with them.

4. Support

4.1 Have there been changes to the support you get during the Coronavirus outbreak?



61% of respondents had experienced a change in the support they receive during Covid-19.

Additional comments about changes to support:

i. Changes to support at home (17)

- Received less support or it had not been when they wanted it (7)

'I have less support. My staff won't come into my flat for weeks, it got very dirty and untidy. I got depressed and lonely.'

- Found it difficult having different support workers (6)

'I have had support from people I do not know very well. They have been nice but I miss my usual staff'

- Changes to patterns of support or procedures (4)

ii. Difficulties not being able to access support via support groups, day services, voluntary work, college and regular activities (13)

'I like a routine but that has stopped during the outbreak. Been at home since March. My day services stopped, I really miss them as I love going out and being with my friends'

'Unable to access support groups so am very socially isolated'

iii. Moved back in with parents or had more support from parents during the outbreak (12)

'As in lockdown no support coming in down to Mum and Dad doing all my support'

iv. Importance of being able to maintain contact with support and others when at home, including Zoom chats and regular phone calls (11)

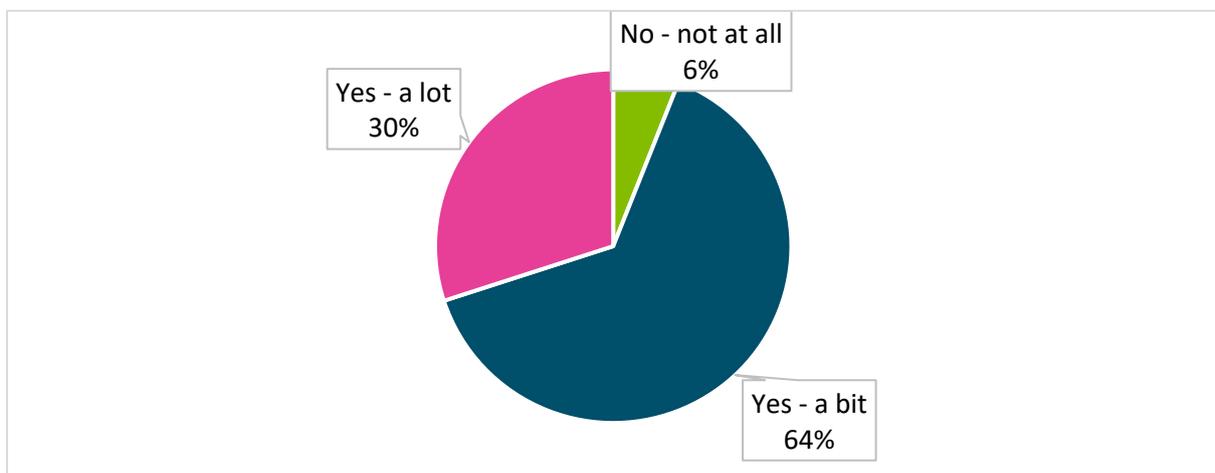
v. Comments giving praise for support / support workers and how they have supported individual during the outbreak (9)

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

Other comments about support included the impact on families of increased caring role, being worried about support workers getting ill, not wanting to leave the house due to risk of Covid-19 and two people saying they are not currently receiving any support.

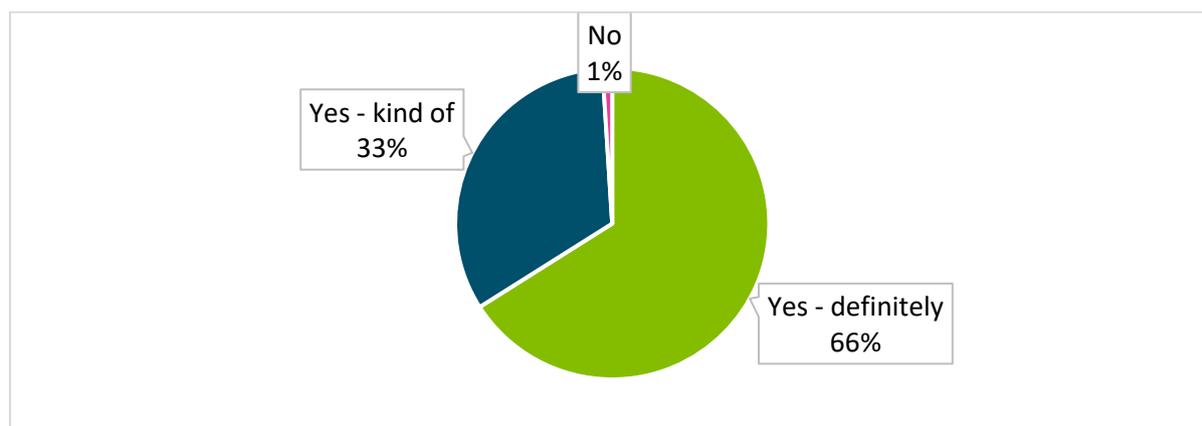
5. Mental Health and Emotional Wellbeing

5.1 Has Coronavirus and staying at home made you feel sad or worried?



Most people (94%) told us that Coronavirus and staying at home had made them feel a bit (64%) or a lot (30%) worried or sad.

5.2 If you have been worried or sad, have you been able to talk to someone?



66% of people thought they definitely had someone they could talk to about this and 33% the other respondents said yes - kind of.

5.3 Additional feedback about feelings and impact of Covid-19

i. Missing friends, family and activities such as day service (20 people)

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

'I feel very lonely and have missed my friends and talking to people'

ii. Feeling worried or anxious (18 people)

'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.'

iii. Impact on routine and difficulties with uncertainty (9 people)

'I have missed my routine'

'I really hate the uncertainty'

iv. Importance of support workers and family to make them feel better and keep in touch with others (9 people)

Other issues mentioned included finding wearing a mask difficult, a lack of support for mental health and a lack of understanding of disability. Two people told us they had lost a close relative during lockdown.

‘Wearing masks is difficult for me. I have problems with my speech and wearing a mask restricts my communication’

‘There is no one to talk to about the mental health affect lockdown has created’

‘Very scared things have changed so much... autism has got worse, more angry and frustrated and hate wearing masks’

Responses from our main Covid-19 survey included two people commenting about the lack of support available for people with Autism. One person also told us the reason they had been unable to access support for mental health was that there was nothing available via Healthy Minds for people with Autism.

5.4 Online communication and video calls

We heard how valuable many people have found being able to keep in touch online over lockdown, by attending Zoom sessions and meetings organised by Our Way and SpeakEasy N.O.W. 10 people commented about learning how to use Zoom, other ways of communicating online and new skills during lockdown.

‘Learnt how to use Zoom, this has allowed me to keep in touch with friends and my counsellor. We talk and we share our experiences. Together we feel stronger’

However, responses to the survey and those we spoke to from SpeakEasy N.O.W. told us that although they were all finding video calls helpful, they were worried about not being able to see people face to face soon.

‘I miss my friends, speaking to them online isn’t the same’

‘I am looking forward to seeing people face to face again. You can feel isolated’

When we spoke to SpeakEasy members, they also told us they knew people with a learning disability who did not have any access to a computer or smart phone. They also 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. This meant 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.

6. Conclusions and Recommendations

I. Information and Communication

Most people felt they have been able to access information about Coronavirus and keeping safe. However, for many this has been through family and support organisations. People were less likely to access information online and many felt information needed to be clearer and in a format that was easy to understand.

Although some people told us they have learnt more about online communication and found this helpful over lockdown, some 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 a carer present.

Recommendations -

1. Ensure information about Coronavirus, how to keep safe and current guidance about restrictions, is available in an easy to understand format and that people, especially those without online access, can access visual and written information.
2. Consider how people can be supported to access / continue to access and engage with others online while restrictions on meeting face-to-face and daily activities continue.

II. Health Services

People told us about the importance of kind and supportive staff and procedures in place to help them feel safe when they accessed health services. Concerns were raised about the use of telephone and video appointments, feeling anxious about accessing the services and the changes that had been made and not being able to access regular check-ups, including dental check-ups and those for long term conditions. The NHS Long Term Plan emphasises the importance of routine checks such as these and Annual Health Checks for people with a learning disability in reducing health inequalities.

Recommendations -

3. Consideration of difficulties relating to communication, online access and privacy when planning further use of telephone and video calls for health appointments.
4. Ensure people can access information and support when visiting health services, to reduce anxieties and understand changes implemented.
5. Consider opportunities to signpost people to or develop visual resources to help people understand how visits to health services will work. E.g. videos or photos of health service locations and staff.

6. Encourage people to seek medical advice for any health related concerns
7. Ensure people are receiving regular health check-ups and routine care, including Annual Health Checks

III. Support and Emotional Wellbeing

Many people told us how difficult they have found lockdown, the change to their routine and activities. We heard about the importance of care and support from families, support workers and other organisations such as Our Way and SpeakEasy N.O.W. However, some people did not feel they had been able to access support for their emotional wellbeing and some told us they had not received the support they have needed at home. Many people who responded to the survey were living at home, some of whom had returned home for lockdown, increasing the caring responsibilities for families.

Recommendations -

8. Provide assurance that people are receiving allocated / required levels of support at home.
9. Consideration about how anxieties related to Coronavirus and changes to normal activities can be supported.
10. Recognise importance of opportunities for people to meet up face to face and activities to restart to emotional wellbeing.
11. Ensure there is information and support available as people start going out more, to reduce anxieties and maintain independence.
12. Ensure there is information and support available, which is appropriate and accessible for people with a learning disability and Autism, in relation to mental health and emotional wellbeing
13. Consideration about impact on family and carers of additional caring responsibilities and how this is being supported.