



Health and Wellbeing Group



Our Long Term Plan

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Topic: Easy Read



Feedback:

People are still getting letters, forms and information that are not accessible to them. Here are some examples groups members have received recently that are not easy-read and they could not understand by ourselves:



- A 2 page letter from a GP surgery in small writing about shielding during the pandemic. I couldn't read a lot of it. It confused and worried me.
- A referral form from TalkWorks sent by email (when referred from GP). I didn't understand it all and couldn't fill it in by myself.



The two people in the above examples are registered as having a learning disability with their GP surgery and have asked for easy-read information.



In both examples above, people got help from Devon Link-Up (a charity) to read the letters, fill in the forms and write an email to ask for easy read or support. They do not have social care support, so this was not an option.



Accessible Information Standard

Members want to know what to do if people continue not to give them easy read when they ask, or if people refuse. One member explained that they asked at their GP surgery but were told they didn't have access to get easy read. Another asked at an opticians and was refused.



Members think there should be a place they can ring or get in contact with to:

- Ask for advice and complain.
- To access common easy read medical information.



Actions we can take as a group:

Raise awareness of easy read information in GP surgeries. Make a video about showing what happens if there is no easy read using examples from group members.



Make a card about easy read and The Accessible Information Standard that people can show places like GP surgeries and opticians. Sometimes people feel shy and worried so would be good for them to just show.



Who we think can help:

- Local politicians and councilors could help raise awareness.

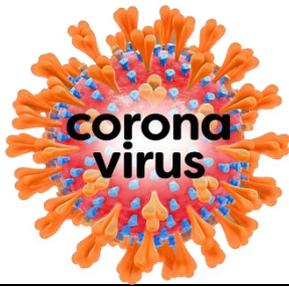


- Representatives from local GP surgeries.



- The Care Quality Commission

Actions taken with dates:



Topic: Covid-19 and GP Services



Feedback:

Some people are finding it harder to access GP services with covid-19 restrictions. Here are 2 examples:



- During the first lockdown, I could not get hold of my GP surgery on the phone and I needed to contact them to re-order important medical kit I have for my crohn's disease. It said on the phonenumber to book online or by email but I did not know how to. I called Devon Link-Up who supported me by writing an email.



- I have a hearing impairment so I cannot hear well on the phone. I usually go to the surgery to speak to the receptionist. When I tried, someone came outside and said you can't come in and that I must ring. I wanted to ask what to do but they made me feel like I had to go straight away. I was upset and I didn't ring.



Self testing

I found the instructions hard to follow for a self-testing kit and I missed the bit about how to put box back together. The courier wouldn't take it so I called the helpline to ask for another test. They said I couldn't and to go to a testing centre. I said I didn't have a car so they said to go into a walk-in centre. I didn't think this was safe so stay inside for 10 days. A staff member from Devon Link-Up got shopping for me. I haven't had any leaflets about people who can help get your shopping if you can't go out.



Actions we can take as a group:

- 1) Raise awareness of learning disability register and summary care records to members of DLUP and partnership board members. We can use the website and Facebook.**
- 2) Write to local GP surgeries to tell them people's experiences so they can improve. Make some suggestions to them, for example sending easy read letters to people on the learning disability register about how to make contact.**
- 3) Contact the NHS COVID-19 testing company to share people's experiences and to ask how they are supporting people with learning disabilities to take tests.**



Who we think can help us:

Clinical Commissioning Group as they are in contact with GP surgeries.

The Care Quality Commission

Actions taken with dates:

	Topic: Learning Disability Training
	Feedback:
	Actions we can take as a group:
	Who we think can help us:
	Actions taken with dates:



Topic: Annual Health Checks



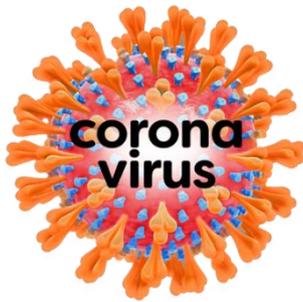
We do not do annual health checks.



Feedback:

Members looked at a questionnaire about annual health checks that was completed by 39 people across Devon in January 2020. Members also shared their own experiences of annual health checks. They also discussed their own experiences. Here were some of the main points discussed:

- Members are concerned that GP surgeries do not all offer annual health checks and can refuse to do them if asked. One member moved GP surgery because of this.
- Every single person in residential care had an annual health check. Many people who lived independently did not.
- 1 person out of 39 received an easy read letter about their annual health check.
- No one said they had a health action plan or received any easy read guidance after their check. Members could not remember everything that happened in the check.



- There are concerns that these health checks are not going to happen with the pandemic.
- One group member has had annual health checks in the past 9 months. No other members have.



Learning Disability Partnership Board



Actions we can take as a group:

- Increase awareness of the Learning Disability Register and Annual Health Checks. We can do this through Devon Link-Up members and the partnership board.
- Use Facebook and the website to increase awareness.



Who we think can help us:

- The Clinical Commissioning Group (CCG) as they commission GP services.
- Representatives from local GP surgeries.

Actions taken with dates:



Topic: Mental Health

Important Notes:

There are concerns that people with learning disabilities do not get the same access to mental health services because:



- Staff and professionals may not recognise someone having depression or anxiety because they put it down to their learning disability.



- People with learning disabilities may not know much about mental health and recognise it themselves.



- Mental Health services are not all accessible for people with learning disabilities.
- ‘Social prescribing’ models that are being used to help people with mental health problems may not be accessible.



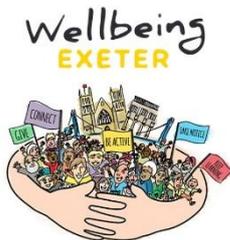
Members are concerned that there may also be increased mental health problems for those with learning disabilities with the covid-19 pandemic. This has meant some people are unable to leave residential homes, see family and friends and are very isolated.



Actions we can take as a group:

Increase awareness of recognising mental health problems for people with LDs and healthcare professionals. We could make a video.

Find out if social prescribing projects like Wellbeing Exeter are supporting those with learning disabilities.



Who we think can help us:

GPS

Talkworks

Wellbeing Exeter

Other projects like Time to Talk (Living Options)

Actions taken with dates:



Topic: Epilepsy Awareness and Training



Important Notes:

One member of the group is particularly concerned about epilepsy awareness and training.



10 years ago they experienced security staff outside a pub ignoring him when he was trying to get help as he was having an epileptic fit. Since then, he said it hasn't got better and people have still walked past him when he was having a fit. It makes them very anxious about going out.



They think more staff who work in public organisations should have training. For example, people who work in libraries, cafes, restaurants and shops.

They think this training should include how to recognise if someone is having a fit and what to do to help them.



What we can do help as a group:

Make a video or story to share.



Contact media to share experiences and raise awareness in general.



Look at first aid and see if it includes epilepsy training – getting it included in first aid training would be a great way to increase awareness in public places.

The logo for Epilepsy Action, featuring the word "epilepsy" in white lowercase letters on a blue rectangular background, and the word "action" in pink lowercase letters on a pink rectangular background to its right.

Who we think can help us:

Epilepsy Action



People who provide first aid training like St John's ambulance

Actions taken with dates: