





Learning Disability Partnership Board

Thursday 10th December Zoom

Minutes

1.1 People at the meeting		
Graham Lewis	Healthwatch- Co Chair	
Neil Adams	Speak Out Leader- Young people-co chair	
Sean Nightingale	Speak Out Leader East Cambs and Hunts-	
Michelle Mansfield	Independent member	
Debbie Drew	Healthwatch	
Helen Kewley	Independent member- family carer	
Russell Henke	Speak Out Leader - High Support Needs	
Bill Jones	Speak Out Leader - Cambridge and South Cambs	
Elspeth Jones	Speak Out Leader	
Julia Rutherford	Voiceability	
Travis McClennan	Access champion	
Tracey Gurney	CCC Finance	
Assunta Genovese	Network Team	
Amanda Preston	Enabling Independence	
Dennis Pinshon	Independent member- family carer	
Bianca Cotterill	Family Carer and Pinpoint	
Siobhan MacBean	CCC disability social care 0-25	
Anita Hewson	CCC SEND	

Sarah Hillier	Enabling Independence
Joseph Simon	Independent Member-Family Carer
Jacky Cozens	PCC
Maddy Hill	Commissioner CCC PCC
Jason Merrill	Family Voice
Roger Valentine	Peterborough Information Network
Harriet Rowe	Commissioner for Adults CCC
Caroline Nightingale	CPFT
Janine Newby- Robson	Healthwatch
Gareth Peters	CCC
Susan Sadek	Clinical Commissioning Group

1.	Who couldn't come to the meeting today? John Brundle, Vincenzo Petruzziello, Tina Plume
2	What we have to say- independent members The Network team and Speak out council were thanked for their presentations that were shared before the meeting. The Network team raised a few issues around health which they have fed back to Healthwatch. - People needing more time for appointments - Trouble bringing someone with them - Russell reported that someone had gone to hospital via ambulance and had requested a carer to attend. Dennis said there have been some mixed messages coming from the hospital as to who can be accompanied and who cannot.

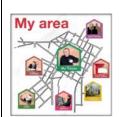
Janine said the Learning Disability nurses in the hospital are keen to help so ask for them.

Michelle reported her GP said annual LD reviews are not a priority.

Debbie said she had managed to organise a face-to-face appointment for both her daughter and Sean but had to ask as was first offered phone call.

Anita says they are asking those over 14 now when they do their EHCP whether they have had a LD health check.

3.



Update from the Learning Disability Partnership and SEND

Gareth said it has not been possible to run the Cambridgeshire locality meetings due to Covid-19.



Day centres have been partially open but with limited numbers.

The team have been keeping in touch with carers but have been working remotely.

Dennis said he had instigated a conversation with the team in Peterborough, but no one had phoned him.



PPE is now available for people who have a direct payment and employ their own staff

In January more of the therapy services will be back in place.



A question was raised about those with Downs Syndrome being stopped from attending some groups.

Work has been done to look at each person as an individual and check what the risk would be.

Helen said she had been told her daughter should not be going to Moving On but she contacted the team and they agreed that she could go as she was low risk.

Gareth said they are trying to work with what is best for all people.

Sean has had not been able to go back to TAG and has had no contact recently. Initially told its because his care needs were not great enough.

ACTION Gareth will check the situation for Sean



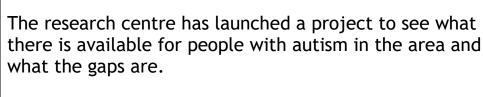
Gareth said they have been working with those in supported living to improve their access to things during covid-19. They have been working with the carers to make things better for those living there.



Maddy says they have been working with teams to see what is needed.



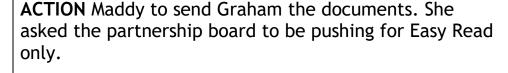
In the New Year they will be seeing if things could have been done differently.





Tracey suggested the autism consortium would be good to consult.

Elspeth and Joseph attend this.





The Network Team had someone talk to them about housing. There are new places being built and some care homes are changing to supported living.

The team feel that there is a need for more different types of accommodation.



Siobhan The team have had difficulties working as normal and have found that IT has been an issue for many people.

Schools and colleges have been quite helpful. Its been difficult for some families with children needing to isolate and the teams have been planning with these families what support can be put in.



Anita The teams are working on plans in case there are increased concerns. We are mapping where children live and checking what providers there are of children's activities.

The three children's homes are now being run by CCC.

4.

GP Websites- Janine Newby-Robson



Janine gave a presentation about the work Healthwatch had done looking at GP websites.

Healthwatch volunteers looked at 96 websites to check if the information was up to date and easy to find.



Elspeth asked if the volunteers had checked the sites were available on phones.

All volunteers had looked on laptops or Ipads. Maybe next time they could try phones too.

Jason suggested that the GPs Patient Participation Group could look at the report

ACTION- Janine and Jason to share contact details

Janine asked that if people looked at their GP website could they feedback to Healthwatch how easy or difficult it was to find out things

5.

Updates from other meetings.

The Adult Social Care Forum has now met. The issue around PPE for PAs was discussed.



The Healthwatch health and care forum meetings have been taking place.

Michelle attends the Fenland one, Bill the Greater Cambridge one, Sean the Huntingdonshire one and Dennis the Peterborough one.

Michelle said she finds the really useful and this time they discussed the BMI you can do it campaign.

ACTION- Debbie to share the dates of them all.

6.



Learning Disability Mortality Review- Susan Sadek

Susan works for the Clinical Commissioning Group (CCG)

They have been looking at the deaths of people with learning disabilities to check if anything had gone wrong. These were just people with LD not those who had autism unless they had a LD too.

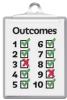


There have been 135 deaths since 2017 and the team have looked at half of these. They are asking questions like

Was there poor health care?
Was there a lack of care support?
Did someone miss something that could have helped that person live longer and better.



Jason asked why it had taken so long to get this done. Susan said they did not have any staff to do this until this year.



Gareth asked what were the findings so far? Susan said they were like what has been happening across the UK

- Most people had good quality care
- There were problems with constipation and toileting
- There was not much specialist end of life care
- There is not an equal opportunity for people to annual health checks



Debbie asked if they were sure they got to see all of the deaths of people with LD? Sometimes as those people may have a physical disability too and a mild LD this could be missed.

Susan said they ask lots of questions. Anyone who is known to social care teams would be picked up, but family members / staff can also check if an individual has been included. This is from 2017 only



Anita asked what age range.

It is from 4 upwards but with children they work closely with the child death review teams.

It was asked if there was a difference in findings between adults and children.

This information has not been separated yet.

7.



Minutes of Last Meeting and Action Log

Minutes were approved.



Action log

85. Julia has started conversations. The Speak Out Council now have a new Fenland Rep.

97. Financial assessor coming to March meeting 126.we are still awaiting Cambridgeshire to have paperwork in easy Read.

128. These have not been happening. Is there something similar in Peterborough?

139. awaiting CCG decision

140-143 completed

144- on hold for now



Date of next meeting:

18th March 2021