

The Joint Learning Disability, Autism and Carers Service Users Event

Held on 1 June 2021



Who was there

Name	About them
Mike Hooper Helen Newton	Healthwatch Cornwall
David Allkins	Cornwall Council & Self-Advocate
Sandra Ward	Chair of Carers Partnership Board, Director of Parent Carers Cornwall & Carer
Amanda Wilton	Derriford Patient Council & Carer
Christopher Burns	Self-Advocate
Chris Jordan	Self-Advocate
Carly Holmes	Cornwall Womens Centre / Divas
Andrew Gray	Self-Advocate
Heather Davison	Divas, Independent Cornwall Autism Network & Parent Carer
Tazmin Hook	Independent Cornwall Autism Network & Service User
David Burns	Self-Advocate
Sam	Self-Advocate

What we talked about at the meeting



Why are private day services open but not Council day services?

It is a worry that some people may have mental health problems after such a long time away.

Can the Council help with IT and meet people on Zoom or Teams?



Taz is still working with the hospital team on medical cards and hospital passports.

Mike will invite the LD liaison nurses to our next meeting to talk about how to improve hospital passports.



Kate Mitchell, Programme Lead at NHS Kernow, said that taking the Covid vaccination was up to the person, and should not stop access to services.



The Autism Service Pilot scheme at Derriford is going to end this month.

Mike is going to write a letter to say that the group wants it to continue.

Ann Smith and Tina Sanford at Cornwall Council are now leading on the Autism Strategy and the Learning Disability Strategy.



The group made a list of ways that people with a learning disability or Autism could be engaged. Mike is going to send it to the Council.

Nory Menneer, NHS Kernow, had said it is important to look at things like housing and places to live, not just health. Chris said that poverty was a big issue and the DWP should be involved too.



Mike is going to meet with the Divas, Cornwall People First and the CHAMPS to talk about the Making Disability Visible idea.

Taz and Heather will be invited too.



At the last meeting we talked about Do Not Attempt Cardiopulmonary Resuscitation (DNACPR).

In Lockdown 1 more people with learning disabilities had DNACPR orders than there should have been.



The group was scared by this and want it to be fair.

At another meeting, Nory Menneer, NHS Kernow, had said that there had been no cases of it in Cornwall.

Amanda had talked to Derriford Hospital. They were doing a lot to make sure that staff understand.



A Learning Disability Liaison Nurse sees every patient within 24 hours.

They did an Annual TEP audit and reported to the Mortality Review Group and the End-of-Life Committee.



Derriford Hospital use the RESTORE2 tool to help to decide if a person is not as well as normal.

Mike has sent it to all the Partnership Boards members so that carers can use it.