healthwatch
Cornwall

Self Advocates and Carers from the Autism and Learning Disability Partnership Boards met on 2 March 2021

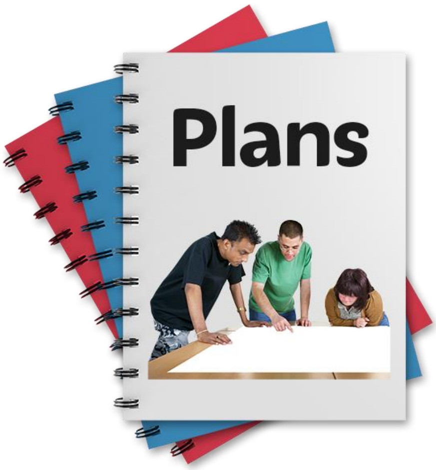
Cornwall Learning Disability
Partnership Board

Attendees

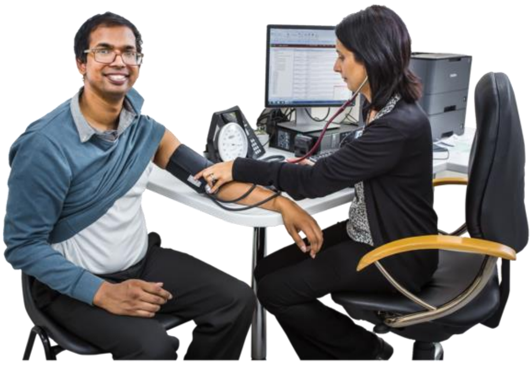
Name	About them
Nuala Kiely Mike Hooper Helen Newton	Healthwatch Cornwall
David Allkins	Cornwall Council & Self-Advocate
Sandra Ward	Chair of Carers Partnership Board, Director of Parent Carers Cornwall & Carer
Amanda Wilton	Derriford Patient Council & Carer
Christopher Burns	Self-Advocate
Chris Jordan	Self-Advocate
Kay	Divas Self-Advocate
Dina Holder Penni Chartress	Cornwall Womens Centre / Divas
Nicky Abrahams	Cornwall Advocacy Supporter
Andrew Gray	Self-Advocate
Heather Davison	Divas, Independent Cornwall Autism Network & Parent Carer
Taz	Independent Cornwall Autism Network & Service User
David Burns	Self-Advocate
Sam	Self-Advocate
Jayne Kirkham	Chair of Learning Disability Partnership Board & Cornwall Councillor

What we talked about at the meeting.

We understand that services can’t open till after lockdown
What will happen then?
Outreach isn’t offered to all .



We want to help with the Learning Disability and Autism Strategies



An annual health check is not being offered to all.
Please can you remind GPs

Hospital Passports

Taz explained about using a hospital passport.
She did not feel that the one in Cornwall is fit for purpose.
She edited one from another NHS Trust

Some are like a credit card and have a QR code which professionals can scan. It will give them your medical information and how you prefer to be cared for.

The group would like to talk more about improving the passports
We will invite the LD liaison nurses to our next meeting.
More people need to know more about them

NHS
University Hospitals
Plymouth
NHS Trust

We want to make sure that hospital passports are the same in Derriford and Treliske

We talked about DNACPR.
It was not easy to discuss.

Nuala explained that it means
Do Not Attempt Cardiopulmonary Resuscitation
It can keep someone alive.
Sometimes it isn’t helpful

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.

The decision should involve us and those who know us well.
We want to talk about it when we are well

Our lives are valuable.

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We may need extra information from a doctor before we help decide if a family or friend should have a DNACPR .

Phone calls are difficult.

Amanda reminded the group that the LeDer report recommends the reSPECT tool when people couldn’t make their own decision.

Dina asked what local hospitals are going to do differently?.

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Covid Vaccination

Some people were confused about how to book their vaccine appointment.

The letter was telling them to go to places a long way from home
Travelling was costly**.**

At the large centres people were not given extra time or Easy Read information..

The vaccinators didn't know that they had a learning disability and/or autism.

Most of the group want the vaccine at the GP practice where people know them.

We would like someone with us..
We don't want to wait a long time to get it.

We would like to know if we can go to day services and have our support workers if we don't have the vaccine.

The group discussed Making Disability Visible

There were lots of ideas about how to let people know about being disabled

It’s a shame that Blue Light Day was cancelled.

We could have an event
Posters, notes, baking

We could use social media
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We will meet again to make plans.

We want people to know about Autism Awareness Week starting March 29th