Minutes
Joint Learning Disability & Autism and Carers Service Users Event
2 March 2021

Note: These minutes include both spoken word and written comments made at the meeting.

Update on what we discussed at our last meeting

Day services

Council run day centres were still closed due to the lockdown. The Partnership Boards team would write to David Coleman at Cornwall Council to ask about plans to reopen.

Heather added that too many day centres had lost their transport so could not attend events such as Blue Light Day and Chris B highlighted the lack of rail links from North Cornwall.

Sandra raised concern that ‘vaccine passports’ could exclude some people from being able to visit certain places.

Outreach

Attendees reported that outreach support offered while day services were closed had been very limited. Some people had only received one hour a week support that consisted only of a walk around the village.

Amanda’s daughter had not received any outreach but the non-Council run day service that she’d attended had had regular contact and provided updates. Her Covid vaccination had been given at the centre along with other day service users.

Learning Disability Strategy and Autism Strategy

The Strategies were a high priority for the Council but progress had stopped due to Covid.

The Partnership Boards team were due to facilitate a meeting on the Autism Strategy between representatives of Cornwall Council, NHS Kernow CCG and the Cornwall branch of the National Autistic Society.

The Partnership Boards team would circulate updates about the Strategies at the earliest opportunity.

What is it like living with a learning disability?

Following Kay’s presentation to the Joint Learning Disability and Autism Partnership Boards meeting in December, Dina said that she had met with Vicki Allen, Cornwall Council, who had been very supportive of raising the profile of safety and abuse.

DNAR Orders

A DNAR Order meant 'Do not attempt resuscitation'. If a patient's heart stopped or they stopped breathing while in hospital a DNAR order meant that the medical staff would not try to resuscitate them through CPR. Receiving CPR did not mean that a person would survive and be able to return to their normal live - only around a quarter of people who had CPR lived and recovered well enough to go home.

Normally a patient had to agree to a DNAR Order. However, there were examples where patients with learning disabilities were not being asked, or they were not listened to, and hospitals were taking the decision.

People with learning disabilities, autism and additional medical needs were much less likely to survive resuscitation and so it had been asked whether it was a good thing to give CPR.

Since Covid, a lot more people with learning disabilities had been put on a DNAR Order without their permission. A form had to be signed by a doctor but it should be done in agreement with the person who was having the treatment or their carer, if that person didn't have capacity to agree. As carers hadn't been able to go into hospital it had been very difficult to involve them and more people had been dying.

Before a DNR order could be signed off there were three things that a doctor needed to consider:

1. Is it likely to work?
2. If CPR could be unwelcome and upsetting for the individual and their family.
3. If it could it lead to poorer quality of life, such as brain damage.

Chris B was concerned that there was no one to stop a doctor in a hospital setting from doing an illegal DNR. Nuala said that it emphasised the importance of patients and families knowing their rights.

Amanda said that the LeDeR report supported use of the reSPECT tool. A person with a learning disability may not be able to say exactly how they felt, which could result in an incorrect diagnosis.

Heather wrote that it was very worrying that lives had been devalued. It was unacceptable to her that people were being considered expendable/too costly and that the culture dynamics seemed to be accepting of DNRs. Taz added that there could not be innovation in care and support without fixing the foundations.

Christopher said that he had been asked by the doctor at hospital to agree to a DNR order for his mum when she went into hospital. His mum didn't want it, so he didn't agree. He said that the doctor was very good and explained it well.

Nuala said that the Care Quality Commission (CQC) had written a report and Dina asked if the hospitals and local doctors could be asked what they were going to do differently because of the report.

Annual Health Checks

Amanda urged everyone to make sure that they had their Annual Health Checks.

Heather said that her brother's annual health check was done over the phone. Sammy had hers last year and It was face to face.

The Partnership Boards team would speak to Vicki (Cornwall Council) and Nory (CCG) and ask them to help to make sure that GPs were doing Annual Health Checks for people because they could help to stop people becoming unwell.

Hospital Passports

Taz thought that the ‘hospital passports’ being used by Treliske didn’t really work and she had found one from another NHS Trust that she preferred. She had edited it for use in Cornwall and would share it with the Partnership Boards team.

Hospital Passports were for anyone who was neuro diverse. It had details of medication, conditions, allergies, emergency contacts etc. People should take It to every hospital appointment as it would help if communicating was difficult.

Many attendees did not know about Hospital Passports

Nuala advised that they could be downloaded here:

Royal Cornwall Hospitals NHS Trust

National Autistic Society

Nuala said that it was important to make sure everybody who needed a passport had one and that medical teams supported them. The Partnership Boards team would invite the Liaison Team from Treliske to come to a meeting and talk to the group about them. They would also ask how Treliske, Derriford and the CCG were responding to the LeDeR report.

Amanda said that a lot of people in East Cornwall used Derriford Hospital so it was important to make sure that they used the same form. She added that Derriford had separate versions of their passports for people with learning disabilities and Autism.

Taz had a medical card that detailed all of her medical conditions that needed to be known to receive first aid. It contained a QR code and an NFC code that enabled paramedics to access the information that would be on her hospital passport but also a DNR, her last wishes and organ donation. She had a meeting with the LD team at Treliske with a view to promoting the cards for use across networks, including the Police and other authorities.

Covid vaccines and next steps

Nuala reported that people with severe learning disability had been prioritised for a Covid vaccination but those with a mild learning disability had not been prioritised. Mencap had successfully campaigned for all to be within group 6.

A letter was going out from National Health England telling people to go to large vaccination sites to get their Covid jab.

If people didn't want to or couldn't travel to them they could wait for their GP to phone them for an appointment nearer to where they lived.

GPs had records of people who were carers or had a learning disability but if people were not already registered as a carer or learning disabled they needed to contact their GP to let them know.

Sandra said that she went with her daughter to get their vaccinations and the staff there were very helpful and friendly. Her daughter didn't want her injection, but the staff helped a lot.

Nuala said that there were trials going on with vaccines that were given up the nose instead of by injection. The results of the trials were not expected to be announced until August but that gave hope that they would be available for winter top-ups.

Penni said that she had to travel from Bude to Truro to have her vaccine which meant she drove past the large vaccination site at the Royal Cornwall Showground to get there. It was OK for her as she could drive but not everyone could and it took up a large part of her day.

Kay said that she had to travel from Hendra Park to Pensilva. She was lucky because she had a friend who could take her but if she hadn't it would have cost her £18 for a taxi.

Some GP practices didn't seem to be offering local appointments but Amanda said that they should be making reasonable adjustments for people who couldn't travel as not everybody had family support. She said that if someone had challenging behaviour and there was no family support the Intensive Support Team, part of the Learning Disabilities Primary Care Team, would help with vaccinations. Heather queried whether such a service was available for people with Autism.

Sandra emphasised the importance of talking through the need for adjustments with the GP surgery when they called to book the appointment.

People who had had their vaccine said that they were not given any information in Easy Read format when they went for their appointment.

From her experience, Kay thought that more could have been done to explain the vaccination on site.

Chris J was having his vaccination later that week and said that he would let the group know how it went.

Christopher B said he was given an information sheet about what to do if he felt unwell after his vaccination but it wasn't in a format that was easy to understand.

The Partnership Boards team would feed two things back to Nory: 1. That upon the National Health England telling people to go to large vaccination sites people were not aware that they would soon be offered that the vaccine centres did not seem to be aware of the need for adjustments to be made for those with learning disabilities and autism.

Heather asked what happened if people didn’t want to have the vaccine, would they be stopped from accessing services, schools etc? The Partnership Boards team would try to find out.

Any Other Business

Making Disability Visible

During the talk about vaccines, Sammy wrote of a recent campaign for people with learning disabilities and Autism to have the vaccine sooner (the radio DJ Jo Wiley had spoken about the matter recently as her sister with learning disabilities had caught Covid). She said that she hoped that it would lead to more recognition of people with disabilities.

All agreed and Dina said that there was a need to get all the brilliant things that everyone did out into the public domain, including the media, Face Book, etc. Chris B wrote that it was a major problem that disability could be made invisible if it wasn’t allowed to be seen by everyone.

Taz suggested a ‘rogue kindness project’ and throughout the meeting people wrote the following suggestions:

- Offer rides to the beach;
- Surprise Amazon gift vouchers;
- Baking for people;
- Create a video showing how everyone helped to make positive changes to peoples lives, the difference that individuals can make;
- Chaos Radio;
- Posting notes that self-advocates designed that say, ‘ You're not alone, You're valued, You're loved"... take them around the streets. Keep quiet and wait for people to come forward (eg. Cornwall Live). Kill the prejudgement with kindness;
- Create posters with positive messages (a poster designed by Chris during the meeting was circulated with these minutes and would be shared at the Joint Learning Disability and Autism Partnership Board meeting later in the month).

Further thought was needed on how to progress the ideas.

Blue Light Day was mentioned and all agreed that it helped to make the wider community more aware of people with learning disabilities but more promotion would help.

Autism Service Pilot Scheme

Amanda said that the Autism Service Pilot at Derriford was due to end at the end of the month but they had agreed to extend it until the end of June.

The Partnership Boards team would write to Kate Bamforth of the Autism Team at Derriford to tell her how good the service was and how important it was that it continued. They would also ask the Liaison Nurses what was happening with ADAPT at Treliske.

International Women's Day

Dina said that Monday, 8 March was International Women's Day if anybody would like to support it. There would be an online event at 4 pm that Monday on the Women's Centre's Facebook page.

World Autism Awareness Week

Nuala said that it was also World Autism Awareness Week from 29 March.

Our next meeting

The next meeting would be at 10 am on 1 June by Zoom.

Like at the last meeting, it was agreed that people wanted to continue with a joint Autism, Learning Disabilities and Carers format and that it should continue to be online even after Covid. Taz said that she did not like the meetings face to face. They were not Autism friendly and people spoke a lot more for themselves from home. David added that keeping the meetings on Zoom took away the difficulty of transport for people.

The Joint Learning Disability and Autism Partnership Boards meeting was on 23 March. Mike would put a video together from this event so that the Board could hear the views expressed.