

Minutes
Joint Learning Disability & Autism and Carers Service Users Event
1 June 2021

Update on what we discussed at our last meeting

Day services

Helen Cahalane from Cornwall Council had said that a letter would be sent to service users very soon. There are more service users in the West but more people in the East had received some sort of service since 12 April. This may be partly because of Covid rules. In the East, 93 people had received a service and 27 people had received no service at all. In the West, 70 people had received a service and 78 had received no service at all.

Members of the group were frustrated as private day services have reopened successfully whilst Council services remain very restricted. They wanted to know how private services were able to meet government guidelines on bubbling, social distancing etc but the Council could not. **Mike said that he would ask for more detailed information before next week's Learning Disability Partnership Board meeting.**

Sandra cited one day service that was only able to take up to 15 people. Users had varying ages and degrees of disability and autism and they were finding it very hard to reintegrate. They were having to start again with all of their practices such as relationships, tolerance, being calm etc, and this was making it very difficult for them to get on with their peers. It was very worrying that numbers showed that some people were not returning, possibly due to mental health issues on top of their pre-existing conditions, and indicated that people could not cope having had such limited support for such a prolonged period.

Helen had said that the people were prioritised for a service through a fair, nationally recognised system. Heather said that the Council used a traffic light system - those with highest need are identified with a red light and they are prioritised to receive services.

Amanda asked what guidance the Council are following for the reopening of day care services and Mike posted this link - [How to approach re-opening day care services \(scie.org.uk\)](https://www.scie.org.uk).

As people had cared for their loved ones at home for 15 months, Heather thought that the Council must have reserves of unspent monies. **Was this the case and, if so, what would that money be used for?**

Heather said that she understood that not all service users received the letter about the reopening of day services that was sent out on 6 April.

Heather said that often only 1-2 hours of outreach is offered a week. Everyone agreed that service users desperately need the return of day services - the most vulnerable people in society are being let down by the Council. **A breakdown of services offered was requested.**

Mike added that he understood that the Council still intended to follow the plans in its 6 April letter but people should be mindful that the Council would have to follow Government rules if the easing of lockdown restrictions is delayed beyond 21 June.

Christopher asked if people had not been offered services due to falling foul of the financial assessments?

Chris Burns questioned why the Council have changed their policy on allowing people to buy laptops with their direct payments. Communication is a basic need and without this service users are being made to feel more vulnerable and isolated while day services are shut. Amanda suggested that Outreach could provide tablets. **The Partnership Boards team will follow up with the Council.**

Heather questioned why the Council had not set up Zoom or Teams meetings as engagement with service users while day services have been shut.

Hospital passports

Nuala had connected everyone with responsibility for carers passports across Treliske and Derriford.

Too many people are still not aware of Hospital Passports, including hospital staff.

Learning Disability awareness is mandatory training for all hospital staff at Derriford and Hospital Passports are promoted as part of that training. Learning Disability Link Workers also promote their use on the wards.

Chris Burns asked whether Hospital Passports could be promoted on social media as part of Learning Disability Awareness Week later in June.

Amanda suggested asking a Learning Disability Liaison Nurse to come to a future meeting to discuss with the group. Mike asked for everyone to send some questions to him by email which he can send through before the meeting so that they can prepare responses. **The Partnership Boards team will invite a LD Liaison Nurse.**

Taz added that she has met with Amy Foxford and Jane Rees to discuss medical cards and hospital passports and they are due to meet again soon. **Taz to update Mike by email, including her plans to involve Derriford and whether she needs any contact details.** Will update again at the next meeting.

Covid vaccinations

At the Joint Meeting of the Learning Disability and Autism Partnership Boards in March it was reported that Kate Mitchell, Programme Lead at NHS Kernow, had confirmed that the decision whether or not to take the vaccination was down to the individual and should not affect access to services. If anybody finds this is not the case, please let the Partnership Boards team know. It is a Human Right to be able to choose not to have the vaccine.

Autism Service pilot at Derriford

Nuala sent a letter of congratulations on behalf of the Board and Amanda has asked whether the 7-day service will continue after the 6-month trial period. An investment plan has been put forward to request funding from KCCG, DCCG and UHP. If the

funding is not agreed the service will end on 20 June. Everyone agreed to send a letter of support from the group and if anybody wants to express their support they should email Nory Meneer at KCCG, Shona Charlton at DCCG and Fiona Gordon at UHP. **Amanda to share email addresses and Mike to share with the group. Mike will also relay to the Board meeting next week.**

Learning Disability and Autism Strategies update

Vicky Allen and Nory Meneer are no longer leading on the strategy updates. Ann Smith and Tina Sanford who both work for Cornwall Council are managing this now. The Autism Strategy and the Learning Disability Strategy will now both feed into an All Age Working Strategy and they are keen to engage through the Partnership Boards and this group.

Each strategy will include four categories - Inclusive Life Opportunity, Where We Live, What We Do With Our Day and Communities, and Keeping Well, and there will be three focus groups looking at Preparing for Adulthood, Housing and Support, What To Do Throughout The Day And How to Maintain Good Health.

This group has been asked to offer suggestions and ideas on the best way to engage with Learning Disability and Autism groups.

Suggestions included:

- Reopen day services and talk to people at those.
- Speak to GP surgeries - they have a wide reach and can share information with people with a LD or Autism that the Council have no knowledge of.
- Libraries and library staff.
- Letter to all service users.
- Support groups and social groups.
- Youth groups.
- Shopping centres and other public places.
- Consider those who are digitally excluded.
- Consider those who do not currently meet the criteria for services but need to be included in communications.
- Private providers - it was essential to include all.

Taz has also created an address book of Autism stakeholders.

Chris Jordan mentioned that local Councillors have a Community Chest Grant that local groups and clubs can request support from. **Mike to ask whether the application forms are in Easy Read.**

Sandra asked who is representing Health on preparing the strategies. Mike added that responsibility for producing the strategies now lies with Cornwall Council. Nory Meneer, NHS Kernow said at the Joint Meeting in March that a Learning Disability Strategy on its own will not incorporate things like housing and accommodation, so it is important to look at everything together.

Chris Burns suggested that the DWP should be involved too as poverty plays a big part. People can't stay healthy if they can't afford to pay for the things that they need to keep them healthy.

Mike to ask which organisations the Council will be working with in preparing the Strategies and send details of the discussion to Ann Smith to cover at the Learning Disability Partnership Board meeting next week and the Autism Partnership Board meeting on 22 June.

Regarding the NAS Not Enough campaign, Tigger and Taz had been due to meet with Vicky Allen and Nory Meneer to discuss the campaign and how it will link with the strategies. Ann and Tina will be contacting Tigger to arrange to discuss further.

Making Disability Visible

The group agreed to meet separately to discuss this in more detail and come back to the Partnership Board with some ideas. Sandra suggested that Cornwall People First could lead on it. Taz also suggested Spectrum and/or Green Light could get involved.

Mike and Nuala are meeting with Dina and Fliss soon and will discuss how to encourage more people to join this group. **Mike to invite Taz and Heather to the meeting.**

Chris Burns said he had recently seen somebody in a mobility scooter who looked like they were not being cared for properly but nobody else seemed to be concerned. Nobody should ever feel that they are being nosy or can't ask whether someone is OK. They may be vulnerable or being abused.

Chris Burns to send a photo of his artwork to Mike.

Mike will tell the Board that the group are going to talk about this in more detail and Laura will speak with her Social Worker and contact Fliss to talk about focus groups.

Any Other Business

DNACPR

Following the last meeting Amanda asked what Derriford were doing differently after the CQC highlighted problems around people with Learning Disabilities being given a DNACPR order without their knowledge. The hospital said that the guidance from the Government is shared in UHP bulletins and printed off and laminated for red wards. It is also available as part of the hospital's important Covid documentation. They do yearly TEP audits and annual reports to the Mortality Review Group and the End-of-Life Committee. The Learning Disability Liaison Nurse also sees all Learning Disability patients within 24 hours of admittance and checks the TEP forms and gives advice as part of the assessment.

Mental Capacity Act training is also available and TEP completion is included as a case study in Junior Doctors training. Any TEP that states Learning Disability or related diagnosis is recorded as an incident and investigated, as it is illegal to cite learning disability as a reason for DNACPR.

Mike added that at the last Board meeting Nory advised that there have not been any cases in Cornwall of anybody not receiving treatment or having a DNACPR order due to a learning disability.

Identifying early signs of worsening health in a person with a learning disability

Derriford use the 'News2' tool and feel it works well for people with learning disabilities. The only discrepancy is not knowing what a normal baseline is especially for those with a profound and multiple learning disabilities, for example body temperature is often lower. Learning Disability nurses are doing a project in the community to set a baseline for people, which will become part of the Patient Care Summary record held by GPs.

Derriford User Group

Derriford are keen to have representation from Cornwall on the user group. They are hoping to have a meeting later this month. If anyone would like to be involved with the group please let the Partnership Boards team know. **The PB team will pass on the meeting details from Amanda.**

Amanda will feed back after the meeting. She is also due to meet with the Learning Disability Liaison Manager soon and will feed back after that meeting too.

Campaign

Taz asked about the Healthwatch and CQC campaign. Mike advised that this is a national level campaign and Healthwatch Cornwall are not involved.