Joint Meeting of the Autism & Learning Disability Partnership Boards

10 am, Tuesday, 23 March 2021

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Agenda

1. Welcome, introductions and apologies

2. Minutes of the 8 December 2020 Joint Meeting of the Autism & Learning Disability Partnership Boards (page 3)

3. Feedback from the 2 March 2021 Learning Disability and Autism Service Users and Carers Event (page 13)

4. Working Age Adults Programme – Ann Smith, Cornwall Council

5. Update on LD and Autism Strategies – Vicki Allen & Nory Menneer

6. LeDeR Update – Nory Menneer

7. Update from the DIVAS

8. Update from the CHAMPs

9. Update from Cornwall People First – Presentation (page 19)

10. Any Other Business

11. Future Meetings – Detailed overleaf

2021 Meetings are set as follows, all are 10am on a Tuesday:

- Joint Learning Disability & Autism and Carers Service Users Event - 1 June – Zoom
- Learning Disability Partnership Board - 8 June - Teams
- Autism Partnership Board - 22 June – Teams
- Joint Learning Disability & Autism and Carers Service Users Event - 7 September – Zoom
- Learning Disability Partnership Board - 10am, Tuesday 14 September - Teams
- Autism Partnership Board - 28 September – Teams
- Joint Learning Disability & Autism and Carers Service Users Event - 23 November – Zoom
- Learning Disability Partnership Board - 10am, Tuesday 30 November – Teams
- Autism Partnership Board - 14 December - Teams

MEETING NOTES:	Joint Meeting of the Autism & Learning Disability Partnership Boards
DATE:	Tuesday, 8 December 2020
LOCATION:	Via Teams

ATTENDANCE

Name	Position	Organisation
Nuala Kiely (NK)	Partnership Boards Officer	Healthwatch Cornwall
Mike Hooper (MH)	Partnership Boards Officer	Healthwatch Cornwall
Helen Newton (HN)	Administration Officer	Healthwatch Cornwall
Allison Kirk (AK)	Learning Disabilities Community Nurse	Cornwall Partnership NHS Foundation Trust
Amanda Wilton (AW)	Representative of the Patient Council	University Hospitals Plymouth NHS Trust
Anne Bowdler (AB)	Primary Care Liaison Nurse for Adults with a Learning Disability	Cornwall Partnership NHS Foundation Trust
David Allkins (DA)	Revenue and Benefits Admin Assistant and Self Advocate	Cornwall Council
Dina Holder (DH)	Community Engagement Manager	The Women's Centre
Fliss Hedge (FH)	Outreach Inclusion Worker	Cornwall People First
Heather Davison (HD)	Carer and self-advocate	
Jane Rees (JR)	Learning Disability and Autism Team Manager	Royal Cornwall Hospital NHS Trust
Jayne Kirkham (JK)	Councillor and Chair of Learning Disability Partnership Board	Cornwall Council
Jenna Pulley (JP)	Director	Cornwall Partners in Care
Kay Riley (KR)	Self-Advocate	DIVAs
Sgt Kevin Silver (KS)	Diverse Communities Team Leader for Cornwall	Devon and Cornwall Police
Lucy Fremantle (LF)	Adult Asperger's Assessment Team	Cornwall Partnership NHS Foundation Trust (previously under Outlook South West)
Neil Oats (NO)	CHAMPS	Cornwall Council
Nicky Abrahams (NA)	Project Worker and Advocate	Cornwall Advocacy
Nory Menneer (NM)	Clinical Lead and Programme Manager for Learning Disabilities	NHS Kernow Clinical Commissioning Group
Paul Toon (PT)	Contract Manager, Health Works for Cornwall	Seetec Pluss
Paula Volkner (PV)	Project Manager, Transforming Care Programme	NHS Kernow Clinical Commissioning Group
Penni Charteris (PC)	Community Engagement Worker	The Women's Centre
Rebecca Jelbert (RJ)	Clinical Psychologist, Adult Asperger Assessment Team	Cornwall Partnership NHS Foundation Trust (previously under Outlook South West)
Richard Gittens (RG)	CHAMPS	Cornwall Council

Sam Edwards (SE)	Nurse Consultant, Learning Disability Service	Cornwall Partnership NHS Foundation Trust
Sandra Ward (SW)	Parent Carer and Chair of Carers Partnership Board	Parent Carers Cornwall
Shelagh Mitchell (SM)	CHAMPS Manager	Cornwall Council
Steph Wilton (SW)	Self-advocate	DIVAs
Tasha Milton (TM)	Disability Employment Advisor covering North Cornwall	Job Centre Plus
Tazmin Hook (TH)	Self-Advocate, lead for ICAN and Support Worker	Independent Cornwall Autism Network
Tina Sandford (TS)	Learning Disability, Autism and Transitions Manager for Working Age Adults	Cornwall Council
Tigger Pritchard (TP)	Autism and PDA Advocate, Consultant and Trainer	National Autistic Society Cornwall
Vicki Allen (VA)	Adult Social Care Commissioning Manager with responsibility for Learning Disability and Autism	Cornwall Council

APOLOGIES

Name	**Position**	**Organisation**
Caroline Finlayson (CF)	Speech and Language Therapist	Cornwall Partnership NHS Foundation Trust
Chris Elliot	Carers Forum support worker	Kernow Carers Group
Deborah Rees (DR)	Clinical Review Officer for the Transforming Care Programme	NHS Kernow Clinical Commissioning Group
Ebony Rose Thomas (ET)	CHAMPS	Cornwall Council
Elizabeth Campling (EC)	CHAMPS	Cornwall Council
Georgia Jenkin	Community Care Co-ordinator, Adult Care and Support	Cornwall Council
Gill Pipkin	Chief Executive	Citizens Advice Bureau
Ginette Trewen (GT)	Senior Employment Support Officer	Employability Cornwall, Cornwall Council
Helen Childs	System Director - Integrated Communities	NHS Kernow Clinical Commissioning Group
Katherine McQuay (KM)	Social Worker, Kerrier North	Cornwall Council
Katie Wheeler (KW)	CHAMPS	Cornwall Council
Katy Neve	Senior Educational Psychologist	Cornwall Council
Kerry Crawley	Principal Adult Health Practitioner	Cornwall Council
Laura Truswell	Project Manager	Mencap
Lesley Saunders	Coordinator	Shared Lives South West

Linda Byrne	Veteran Support Coordinator	Kernow Carers Group
Martin De St Aubin	Business Development Manager	Mencap
Michelle Lobb	Carer	Parent Carer Council
Neil Carpenter (NC)	Volunteer Advocate, principally for people with LD	Cornwall Advocacy
Sarah Thorneycroft	Housing Strategy & Partnerships Engagement Officer, Economic Growth & Development Directorate	Cornwall Council
Scott Fuller (SF)	Adult Social Care	Isles of Scilly Council
Stuart Whittaker	Regional Operations Manager	Mencap
Suzanne Wixey	Service Director Adult Social Care and Support	Cornwall Council
Vaughan Temby	Community Engagement Manager	Disability Cornwall

ACTIONS AGREED AT THE MEETING

Action	Responsible	Status
VA to get clarity for the next meeting around day services and respite.	VA	
Sharing PB member contact information.	NK / MH	
Circulate details of the work of the Learning Disability governing body.	NK / NM	
Connect DH and VA.	MH	Completed 08/12/20.
Provide LeDeR update in new year.	NM	

Item	What was discussed	Action
1.	**Welcome, introductions and apologies**	
	NK welcomed all, explained meeting etiquette and gave an overview of the agenda. Everyone present introduced themselves.	
2.	**Minutes of the Joint Meeting of the Autism & Learning Disability Partnership Boards held on 13 October 2020**	
	The minutes of the Joint Meeting of the Autism & Learning Disability Partnership Boards held on 13 October 2020 were confirmed as a true record. Responses to the three actions related to outreach and Direct Payments were awaited from Amy Claridge. Cornwall Council had informed JK that 50% of those previously attending day services were currently receiving outreach in the form of phone calls and other	

means. There had been a delay in bringing respite beds back online due to the second lockdown but they were now being provided on a reduced basis to allow for social distancing.

With regard to management of Direct Payments relating to day services, there was information on Cornwall Council's website detailing how payments could be managed differently. The Government had also issued guidance for commissioners and service users which NK had circulated a link to.

NK added that she had written on behalf of the Joint Board to David Coleman, Head of Service, to ask why the letter that was issued about day services was not available as an Easy Read version. David expressed his apologies and explained that the letter had been issued in extraordinary circumstances. Cornwall Council were committed to providing Easy Read versions of communications in the future.

3. Feedback from the 3 December 2020 Learning Disability and Autism Service Users and Carers Event

NK updated the meeting on the discussions of the Learning Disability and Autism Service Users and Carers Event, held on 3 December 2020.

Discussion took place regarding day services and it was noted that there had been no further communication regarding next steps. Whilst everyone understood that services would not get back to normal for some time, people were keen receive an update and reassurance that thought was being given to restarting services. Cllr Kirkham confirmed that she was under the impression that it was likely to be Spring before normal services resumed.

The meeting considered key areas for engagement when developing new strategies and policies, including:

- GPs and Health
- My Safe Place – Housing
- Learning Working and Volunteering
- Having Fun – being in the community

An easy read summary of the views of the group would be circulated with these minutes.

HD said that those with higher functioning autism could live independently but because communities may not accept them, they could feel very isolated. She would like to see supported living for 'like-minded' people in a community which understood them. This would lead to less isolation and less likelihood of victimisation for being different.

PT advised that Pluss CIC was actively seeking people with learning difficulties, disabilities and their carers/support networks to be part of a people panel to enable them to shape employability services for the future. If anyone was interested and would like more information, they could make contact at paul.toon@seetecpluss.co.uk.

HD also pointed out that whilst private day centres were open, Council respite and day services were still closed as the centres were being used for those leaving hospital before returning home.

	NK advised that day centres operated differently, according to size of buildings etc., however the matter was part of the response awaited from Amy for a Claridge. NM suggested speaking to the Bed Bureau to find out more information on people being discharged to respite centres. TS understood that service users of Council run respite centres had been contacted by centre staff to ensure they were managing. Families with significant risks at home had been offered respite at Lowenna in Truro. Day service staff had maintained contact with people at home and had provided some outreach support where needed. Tregarne was being used for hospital discharge during the crisis period. The intention was to start to use it again in the near future for respite, though timescales were unclear. It was very difficult without usual support services in place and everyone was doing as much as they could to provide safe support, with those at highest risk being given priority. TS advised that she had moved to a new role as Learning Disability, Autism and Transitions Manager. She worked closely with those running respite and day centres and was keen to hear from the Board about how Social Workers and Case Workers could work with them, as well as what needed to be done better. Cllr Kirkham requested that an update from Amy be circulated to the Chairs before Christmas. NK would be contacting AC for all outstanding matters. DH reported that she had been approached by Lyndhurst and the Newquay Day Centres to understand how they could better engage and communicate with service users at the current time, which showed that work being done. AB noted, with regard to people being on the Learning Disability and Autism register, that a flagging system was being introduced as part of the NHS Long Term Plan. It was a work in progress and was likely to take some time to fully introduce. TH requested details of the all the organisations represented on the Board and the services that they offer. NK/MH would look at how this could be done whilst adhering to General Data Protection Regulations.	VA to get clarity for the next meeting around day services and respite. NK/MH to investigate.
4.	**What is it like living with a learning disability? A presentation from the DIVAS**	
	KR, a member of the DIVAs, gave a presentation on what it was like to live with a learning disability. She had also presented to the Learning Disability and Autism Service Users and Carers Event on 3 December 2020. She explained that disabled women and girls were three times more at risk of domestic abuse and sexual violence than non-disabled women, and two and a half times more likely to experience domestic abuse over their lifetime than non-disabled women. Unfortunately, very few women with learning disabilities reached out to specialist abuse services and KR was keen to change that.	

	Learning disabilities were not always visible or obvious and anyone who was unsure whether someone had a learning disability should be encouraged to ask clarifying questions in a sensitive and clear way. Divas could provide training for anyone who was interested. KR shared some details of her own story and her aspirations for the future, including that she would very much like to look after older people in a care home. DH explained that with the right support, KD was able to do the same things as a person without a learning disability and did not want to be treated any differently. SW offered to introduce Kay to a care home where she undertook work experience and PT said that Health Works for Cornwall could help her find work with the support of one of their specialist change coaches. KS added that he had participated in some of the training sessions that had been run for the Police and could highly recommend them. Everyone thanked KR for her inspirational presentation.	
5.	**NHS Kernow and Adult Social Care Update on Supporting Adults with a Learning Disability and/or Autism**	
	NK reported that herself and MH met with VA and NM to discuss the development of the Learning Disability and Autism strategies. VA said that the first initiative was around better integration between health and adults social care. There were a number of joint senior director posts in NHS Kernow and Adults Social Care, so there was a drive to work better together as organisations but also to work better with service users. The team were keen to hear feedback about any issues, what was working well and what could be improved. Another area that was in the proposal stage was individual service funds. These were a personal budget in respect of an eligible health and social care need, held and managed on a person's behalf, to help deliver the outcomes from an assessment of need. A pilot would be run to see if this would be a workable option for people. It was clearly articulated in the Care Act so the team were working together to put a proposal to the Joint Senior Decisioning Team for NHS Kernow and Adult Social Care. A further update should be available after Christmas. Through the Transforming Care Partnership, the team were also looking at developing small support providers for people with more complex needs, developing small providers than could work in a more intensive way with people. There would also be a Working Age Adults Programme, for those aged between 16 and 64 years old, with a range of enduring needs e.g., Learning Disability, Autism, mental health or physical disability. It would enable mapping of where needs still exist, part of which would be around an 'accommodation with care strategy' to develop supported living services. NM said that the NHS Kernow website contained updates from the Learning Disability governing body.	NM to send details to NK to circulate.

There were three to four main focus areas:

Physical health in relation to Covid – there had been a lot of work around the application of treatment escalation plans, which looked at how people would be treated after contracting Covid. Some alarms were raised both nationally and locally as to whether doctors working with families and individuals made decisions about whether people were resuscitated and the work was on making sure that were no blanket DNACPR's (Do not resuscitate instructions). The team were currently working with primary care providers to make sure that was done properly with individuals and families, adhering to the Mental Capacity Act.

Annual Health Checks programme – GPs were now commissioned by NHS Kernow and not by a national programme so communication with GPs was improved. The Primary Care Commissioning Team were working to ensure annual health checks were carried out for at least 67% of people with learning disabilities who were eligible.

Covid vaccination programme – AW and SW asked whether the Covid vaccine would be available as a nasal spray like the flu vaccine. NM said that the vaccination was currently only available through injection, so work was being undertaken on desensitisation for people who were phobic of needles.

At the beginning of the pandemic, a joint leadership team was set up between Cornwall Council, NHS Kernow, Cornwall Foundation Trust and the two acute hospitals in Cornwall to deal with any issues around communication, particularly around Covid. That was continuing but it was unclear what the future would be for the group.

The Transforming Care Programme focused on adults with a learning disability, autism, severe mental illness and/or challenging behaviour that were in hospitals out of county. There had been a significant decrease in such placements and a move to support people locally. However, there had been a significant increase in admissions related to Covid restrictions, for example, when care and support changes had resulted in behavioural issues. There was also a large number of people being discharged back to Cornwall from out of county settings.

It was an important opportunity to make sure money was spent on providing in county care to avoid people needing to be sent to out of county care settings.

In patient peer support had also been commissioned with a local organisation called Citizen Checkers who were contacting people in hospital by video link to check on their safety and ensure they were receiving appropriate quality of care.

Next year the team would be looking at crisis support to make sure that support was provided to people before they required hospital admission.

There were also two user groups of people with lived experiences of being in hospital who were helping to inform the Transforming Care Programme.

NK asked about the impact on the number of mental health beds available when focusing on admitting people to hospital 'in county' rather than out of county and how the extra load was being managed. Was it appropriate to place those with learning disabilities into the environment of an acute ward?

	NM advised that there were no hospital environments that were ideally suited to a person with Learning Disabilities in mental health crisis If people with Learning Disabilities were admitted to hospital beds it meant their placement had broken down. It was essential to discharge as soon as possible back to an appropriate environment. Creating specialist in-patient beds for people with Learning Disabilities was not a solution for people that were experiencing a life crisis. AB added that there was a Mental Health Liaison Nurse who was supporting people with learning disabilities with admissions and the Learning Disability team offered additional support in some cases.	
	AW asked whether there had been any feedback from Covid vaccination trials on the effect of the vaccine on people with Learning Disabilities and Autism or additional health needs. NM said that he had read a paper by the national Joint Vaccination Committee which stated that people with Downs Syndrome and people with profound and multiple disabilities would receive the first tranche of vaccinations, with a caveat that where some people were immune compromised the vaccine may not be as effective. There had not been any specific concerns raised that the vaccine would affect anyone with a learning disability any differently than anyone else. There were, however, caveats around vaccine tolerance in people with underlying health conditions.	
	AW queried whether anyone with a learning disability and compromised immunity had been included in the trials. NM was not aware of anyone but his view was that learning disability was separate to any underlying health condition. Whilst people with a learning disability were more likely to have underlying health conditions, a learning disability was not a factor on its own. In addition, people living in poverty were likely to be hit harder by underlying conditions.	
	DH expressed a view that there had not been much talk about the vulnerability of people with learning disabilities to abuse and financial exploitation and suggested that it should be a focus area for the mental health partnership. Commissioners needed to ensure that staff were aware of issues around sexual violence and abuse and focus on underlying causes rather than just treating symptoms as it could help to address some of the other issues. NM agreed and advised that he will ensure it raised at the Mental Health Cell. There was a lot of work required to adapt therapies to suit people who don’t come under a ‘typical’ group.	VA to liaise with DH to discuss further. MH to provide contact details.
	HD asked whether there had been any progress with new/additional buildings to avoid people having to go into hospitals. NM advised that there was a capital programme from NHS England which was partly focused on keeping people out of hospital. There was money going into buying new housing stock for people who needed specific environments - often to do with specific pasts or people who may be dangerous in non-specific environments. However, there was a need for more adapted environments.	
	HD asked what was happening about autism specific services which would help with prevention. NM replied that NHS England had promised a further £20bn of investment - £400K a year to Cornwall Partnership Foundation Trust to provide a crisis service to people with autism, to capture those people before they were sectioned or detained. It was a community service to support people that had significant breakdowns and was very specifically targeted at those 20 or so people a year who needed crisis care. There was clearly a desire to avoid people getting to crisis point and it was hoped that there would be some investment in that area too.	

	Referring back to a comment that DH made about recognising the signs of abuse or mental hardship, DA stated that Cornwall Council had training modules available for staff on how to recognise those signs. SW asked whether people with learning disabilities who could not be desensitised to injections would have to go through a best interest meeting because of their lack of capacity, and how that would happen. NM said that had not been addressed yet but was in the plan. Where mental capacity applied there would be need to make a best interest decision. That could be done by email or a virtual discussion with the GP. SWi queried what would happen where people had the mental capacity but were phobic. AB advised that a meeting could be arranged to work through phobias and to build up desensitisation over a number of weeks, along with working to make reasonable adjustments.	
6.	**Learning Disabilities Mortality Review (LeDeR) Programme**	
	NK advised that the LeDeR project had been looking at Covid deaths in people with learning disabilities and the SAGE Committee had received a presentation which identified four things that could be done differently to improve mortality rates. It had been identified that people with learning disabilities may not have the same symptoms as other people and also that they may be unable to describe the loss of taste and smell, which was why some people had been misdiagnosed or diagnosed late. There had been issues with 111 call handlers not recognising just how ill some people were and not using some of the early warning tools available. Also, recommendations had been made about having more pulse oximeters in care homes to check oxygen levels and to take additional observations. NM added that the Council and the people who offered care support and accommodation had done really well in preventing outbreaks in care homes. 'Restore' had been used to report on people's health conditions and any possible deterioration. There were various pieces of work around increasing distribution of pulse oximeters to care homes and also ensuring there were no blanket DNACPR's so that people with learning disabilities were treated as equals. Learning disability must never be seen as a factor in deciding whether people received lifesaving treatment. NK said that it was excellent to see those recommendations had been taken on board locally. NM agreed and stated that Jonathan Price, Joint Director of Adult Care and Health, Cornwall Council and NHS Kernow, issued a weekly newsletter which had been really helpful and effective in getting the message across. NK suggested that if there was information in the newsletters that might be relevant to service users and carers the Partnerships Boards team could circulate that. JK was quite shocked when she had learnt that it was younger people with learning disabilities that were dying with Covid rather than older people. She asked how the reviews into deaths of people with learning disabilities were going, as previously they had not been progressing well. NM agreed that the figures were striking but not surprising. Completing reviews in a timely manner had been very poor but staff had been redeployed and a local area co-	

	ordinator appointed to drive the programme forward. The aim was to achieve compliance targets by the end of December. A number of reviewers had been recruited which had been helpful, but it was a slow process. He added that there was a national LeDeR programme and a number of recommendations had come out of its Covid specific report. The themes that were largely around lifestyle and diet, indicating that lifestyle choices were significantly impacting on premature deaths from Covid. The focus in the new year would shift to getting the learnings implemented and NM would update the Board. JK asked whether the Council's Commissioning Care Services were collaborating with the reviews effectively. NM responded that the Council had been excellent in providing information in a timely manner but there had been some issues around GP systems.	NM to provide LeDeR update
7.	**Any Other Business**	
	SW updated on Parent Carer Cornwall and advised that they were busy supporting lots of families with lots of issues. Many parents currently had increased needs and were not getting the support they needed so meetings were taking place with Childrens Services to ensure support was available. The biggest issue currently was transport and getting children with disabilities to school safely. NK asked for any opinions on the future of this meeting. The last couple had been joint meetings of the Learning Disability Partnership Board and the Autism Partnership Board. The next meeting(s) would be in March, when it would unlikely that it would be possible to hold a face to face meeting. It was intended to hold another service user/carer meeting prior to then. The consensus was that the next meeting should be a joint one. If anybody had any thoughts or feedback, it could be sent to the Partnership Boards team at partnershipsboards@healthwatchcornwall.co.uk. KS updated the group. The Police had a Neuro Diversity specialist team and were very aware that 10% of the UK population had some form of neuro diversity. They wanted to address any stigma and negative culture. The child centred policing team were also developing a series of awareness videos on how Police Officers interacted with young people, which would address communication skills, understanding sensory overload and a young person's view of the Police when having Autism. The videos were due to be completed by February 2021 and there were also plans to hold a series of virtual conferences for Police staff to look at how they worked with young people with Autism and learning disabilities. They would welcome any input from partners in supporting the delivery of the videos and conferences. If anybody would like to get involved, please contact Kevin. The meeting closed at 11.55 am.	

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.

Item 9

Forum Feedback to Cornwall's Learning Disability Partnership Board

Face Mask Discrimination

Self advocates have said they feel discriminated against for not wearing a mask, despite having an exemption card on display.

"My family keep badgering me to wear a mask.

I've got an exemption!"

Covid Testing

One self advocate rang the doctor with sickness and was told to get a Covid test or self isolate.

"I've no transport to get to a test centre; I can't go on the bus when I have to self isolate. And I'm scared to do a home test on my own. What if I get it wrong?"

Is there any way people with a learning disability can get help to do a home test on the doorstep?

Isolation and Boredom

People in shared houses spending most of their time in their bedrooms.
"I'm so fed up. I don't go anywhere".

Some SA's have been reaching out online to meet friends and finding that causes its own problems.
"I've had messages from people offering sex".

Weight Gain

Weight gain has been an issue for many self advocates over lockdown.

"I'm really struggling to lose weight".

"I weighed myself and I've gained 2 and a half stone".

"I eat when I'm bored".

Day Services

There’s a lack of information being shared about when day services will reopen.

"I still haven't heard when I'm going back".

When will in house day

services re-open?

Digital Exclusion

So much support and services are online now, those without access are losing independence.

“I need to do everything online now. I have to rely on a support worker to help me. I don't feel independent. "

"...everything is online, I haven't got internet!"

“I need my own email address!”

Personal Budgets

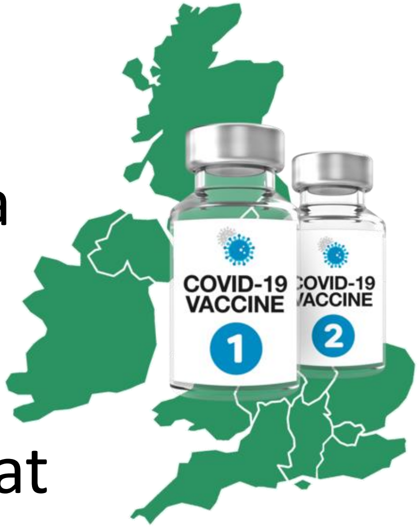
Some people with personal budgets are accumulating money because of limited access to day services and/or PA’s.

Can we have a reassurance that people will be able to use any excess money in line with assessed needs at some point in the future?

Vaccinations

Some people are being offered vaccines at places that they can't get to.

For example someone has been given an appointment at Stithians Show Ground on a Sunday.



Can reasonable adjustments be made so that people can request a different venue?

Who would they need to contact to arrange this?

Needs Assessments

We would like to question the quality and wait time of needs assessments being carried out over the phone.

We have supported two people who have been assessed as not eligible but after requesting a second more thorough assessment, have been assessed as eligible for a support package.

cpf

Cornwall Learning Disability Partnership Board

Thank You For Listening!