

MEETING NOTES:	Joint Meeting of the Autism & Learning Disability Partnership Boards
DATE:	Tuesday 23 March 2021
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 and Carer	University Hospitals Plymouth NHS Trust
Amy Foxford (AF)	Student Nurse Associate	Community Learning Disabilities Team
Christopher Burns (CV)	Self Advocate and Service User	
Christine Bateman (CB)	Advocacy Manager	Cornwall Advocacy
David Burns (DB)	Self Advocate and Service User	
Dina Holder (DH)	Community Engagement Manager	The Women's Centre
Fliss Hedge (FH)	Outreach Inclusion Worker	Cornwall People First
Sgt Flo Linscott (FL)	Diverse Communities Team rep	Devon and Cornwall Police
Hannah Welch (HW)	Primary Care Liaison Nurse	Cornwall Partnership NHS Foundation Trust
Heather Davison (HD)	Carer and Self Advocate	DIVAs and ICAN
Jane Rees (JR)	Learning Disability and Autism Team Manager	Royal Cornwall Hospital NHS Trust
Jenna Pulley (JP)	Co-Director	Cornwall Partners in Policymaking
Jill Barnard (JB)	Specialist Change Coach, Healthworks for Cornwall	Pluss
Katherine Polkara (KP)	Social Worker	Cornwall Council
Maurita Murphy (MM)	CBT Therapist; Doctoral Student	Cornwall Foundation Trust
Nicky Abrahams (NA)	Project Worker and Advocate	Cornwall Advocacy
Nory Menneer (NM)	Clinical Lead and Learning Disabilities Commissioner	NHS Kernow Clinical Commissioning Group
Paul Toon (PT)	Contract Manager, Health Works for Cornwall	Seetec Pluss
Paula Varndell (PV)	Strategic Manager	East Cornwall Primary Care Network
Paula Volkner (PV)	Project Manager, Transforming Care Programme	NHS Kernow Clinical Commissioning Group
Penni Charteress (PC)	Community Engagement Worker	The Women's Centre / DIVAs

Rebecca Jelbert (RJ)	Clinical Psychologist, Adult Aspergers Assessment Team	Cornwall Partnership NHS Foundation Trust
Ruth Featherstone (RF)	Family Information and Access Assistant and Autism Key Worker	SEND Team, Isles of Scilly
Sarah (S)	Family member of an adult with Autism	N/A
Sam Edwards (SE)	Nurse Consultant, Learning Disability Service	Cornwall Partnership NHS Foundation Trust
Sandra Ward (SW)	Parent Carers Cornwall and Chair of Carers Partnership Board	Parent Carers Cornwall
Shelagh Mitchell (SM)	Liaison Lead for Healthy Cornwall and CHAMPS Manager	Cornwall Council
Steve Hillman (SH)	Healthy Lifestyle Delivery Advisor	Healthy Cornwall
Tazmin Hook (TH)	Self-Advocate, lead for ICAN and Support Worker	Independent Cornwall Autism Network
Tim Moss (TM)	Specialist Change Coach	Healthworks for Cornwall, Pluss
Tina Sanford (TS)	Learning Disability, Autism and Transitions Manager for Working Age Adults	Cornwall Council

APOLOGIES

Name	Position	Organisation
Anne Bowdler	Primary Care Liaison Nurse for Adults with a Learning Disability	Cornwall Partnership NHS Foundation Trust
Caroline Finlayson	Speech and Language Therapist	Cornwall Partnership NHS Foundation Trust
Chris Elliot	Carers Forum support worker	Kernow Carers Group
David Allkins	Revenue and Benefits Admin Assistant and Self Advocate	Cornwall Council
Deborah Rees	Clinical Review Officer for the Transforming Care Programme	NHS Kernow Clinical Commissioning Group
Dina Holder	Community Engagement Manager	The Women's Centre / DIVAs
Ebony Rose Thomas	CHAMPS	Cornwall Council
Elizabeth Campling	CHAMPS	Cornwall Council
Georgia Jenkin	Community Care Co-ordinator, Adult Care and Support	Cornwall Council
Gill Pipkin	Chief Executive	Citizens Advice Bureau
Ginette Trewen	Senior Employment Support Officer	Employability Cornwall, Cornwall Council
Helen Childs	System Director - Integrated Communities	NHS Kernow Clinical Commissioning Group
Jayne Kirkham	Councillor and Chair of Learning Disability Partnership Board	Cornwall Council
Katherine McQuay	Social Worker, Kerrier North	Cornwall Council
Katie Wheeler	CHAMPS	Cornwall Council

Katy Neve	Senior Educational Psychologist	Cornwall Council
Kay Riley	Self-Advocate	DIVAs
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
Lucy Fremantle	Adult Asperger's Assessment Team	Cornwall Partnership NHS Foundation Trust (previously under Outlook South West)
Martin De St Aubin	Business Development Manager	Mencap
Michelle Lobb	Carer	Parent Carers Council
Neil Carpenter	Volunteer Advocate, principally for people with LD	Cornwall Advocacy
Neil Oats	CHAMPS	Cornwall Council
Richard Gittens	CHAMPS	Cornwall Council
Sarah Thorneycroft	Housing Strategy & Partnerships Engagement Officer, Economic Growth & Development Directorate	Cornwall Council
Scott Fuller	Adult Social Care	Isles of Scilly Council
Steph Wilton	Self-advocate	DIVAs
Stuart Whittaker	Regional Operations Manager	Mencap
Suzanne Wixey	Service Director Adult Social Care and Support	Cornwall Council
Tasha Milton	Disability Employment Advisor covering North Cornwall	Job Centre Plus
Tigger Pritchard	Autism and PDA Advocate, Consultant and Trainer	National Autistic Society Cornwall
Vaughan Temby	Community Engagement Manager	Disability Cornwall
Vicki Allen	Adult Social Care Commissioning Manager with responsibility for Learning Disability and Autism	Cornwall Council

ACTIONS AGREED AT THE MEETING

Action	Responsible	Status
Circulate information on the reopening of Day Services and respite at the earliest opportunity.	PB Team	Complete. Emailed 6 April 2021.
Send Learning Disability Programme update to PB team for circulation.	NM / PB team	Incomplete. Carried over from 8 December 2020 and 23 March 2021.
NM to encourage the Primary Care Liaison team to cross its registers with those of Adult Social Care.	NM	Incomplete.
Update on Working Age Adults Programme.	AS	Incomplete.
Liaise to ensure timely updates on progress of LD and Autism Strategies.	TS / AS / PB Team	Ongoing.
Provide LeDeR update to PB team for circulation.	NM	Incomplete. No time to present update to 23 March 2021 meeting.

Support for Covid testing.	AB / PB Team	Incomplete.
Convert Direct Payments information into easy read, for circulation.	NK	Incomplete.
Presentation to 8 June 2021 LDPB on the NHS Long Term Plan.	NM (in liaison with PB Team)	Incomplete.
Circulate details of research project on autistic adults who have been assessed by Outlook South West	PB Team	Complete.
Share link to Mental Health Act consultation.	PB Team	Complete.
PB team to consider feedback from members regarding reverting back to separate Boards and schedule meetings accordingly.	All	Complete. All feedback received from members supported reverting to separate Boards. Meetings to be held on previously scheduled dates.

Item	What was discussed	Action
1.	Welcome, introductions and apologies	
	NK welcomed everyone to the meeting and everybody introduced themselves.	
2.	Minutes of the Joint Meeting of the Autism & Learning Disability Partnership Boards held on 8 December 2020	
	<p>The minutes of the Joint Meeting of the Autism & Learning Disability Partnership Boards held on 8 December 2020 were confirmed as a true record.</p> <p>Actions from the meeting:</p> <ul style="list-style-type: none"> VA had not provided an update on the reopening of Day Services and respite. However, Helen Cahalane, Service Manager - Community and Support Services, Adult Social Care, Cornwall Council had assured the Partnership Boards team that an update was imminent. She was very keen to avoid miscommunication and therefore wanted to make sure that service users were the first to receive information, direct from the Council. The Partnership Boards team would then disseminate it more widely. Sharing contact details of Partnership Boards attendees - To share private email addresses without permission of the individual would breach General Data Protection Regulations. If anybody would like to request an email address they could email partnershipboards@healthwatchcornwall.co.uk and the request would be forwarded to that individual to make contact. A list of attending organisations were included in the minutes. NM had not yet provided an update the work of the Learning Disability governing body. However, he advised that he had misstated the matter that he had been referring to, which was the Learning Disability Programme. He would provide an update following the meeting. <p>With regard to the reopening of respite services, SW said that information had been shared but it was in relation to emergency situations only.</p>	<p>PB team to circulate information on the reopening of Day Services and respite at the earliest opportunity.</p> <p>NM to send Learning Disability Programme update to PB team for circulation.</p>

3.	<p>Feedback from the 2 March 2021 Learning Disability and Autism Service Users and Carers Event</p>	
	<p>NK explained the background to the Service Users and Carers meeting and updated the group on the outputs of the meeting held on 2 March.</p> <p>The key areas of concern were:</p> <p>Day Centres</p> <p>Further information on the reopening of day centres would be shared as soon as it became available.</p> <p>Learning Disability and Autism Strategies</p> <p>The group were keen to be involved in formulating the Strategies.</p> <p>Annual Health Checks</p> <p>NM advised that PV was doing a lot of work in this area to improve provision and uptake of annual health checks. 2019-20 saw an uptake of 54% but the work that PV had been doing in the East had increased that figure to 80%. Progress in the rest of Cornwall had been limited, largely due to the pandemic.</p> <p>NHS Kernow were now responsible for the commissioning of primary care and that was creating closer links to GPs and the Primary Care Networks (PCN) that GPs were a part of.</p> <p>The team were working to improve the amount and quality of data coming from GPs regarding where health checks have been done and who was on the Learning Disability register.</p> <p>Health checks for those with severe mental illness had become a priority for NHS England.</p> <p>PV noted that GP practices needed to achieve different criteria to receive payment for health checks and she was holding quality improvement meetings. Discussions had taken place with Healthy Cornwall to create a role to help with this work and there was an opportunity to bring in Care Co-ordinators.</p> <p>NK added that the work specifically related to Learning Disability health checks and did not include autism. Whilst there was no programme for autism health checks there were pilots being carried out in various areas.</p> <p>RF suggested that GPs on the Isles of Scilly were saying that people did not want annual health checks and asked where people should go to put pressure on GPs to offer them. NM advised everyone, where appropriate, to make sure that they were registered with their GP as having a learning disability as that should result in being invited for an annual health check.</p> <p>Health checks were only offered to those over 14 years old and the number of people on the register on the Isles of Scilly had always been low. NM undertook to encourage the Primary Care Liaison team to cross check its registers with those of Adult Social Care.</p> <p>The following link was shared, which provided information on how to get</p>	<p>NM to encourage the Primary Care Liaison team to cross its registers with those of Adult Social Care.</p>

registered for a health check - <https://www.mencap.org.uk/advice-and-support/health/dont-miss-out>

HD suggested it would be good to have an Autism specialist in each GP surgery, along with training in autism to be able to support good communication with and understanding of patients.

Hospital Passports

TH had felt that current hospital passports were not fit for purpose and that more suitable versions were used in other areas. The group would like to look at other options for passports.

TH had been speaking with the Learning Disability Liaison Nurses.

Jane Rees (JR) confirmed that Derriford and RCHT both used the same passport. The passport currently in use had been adapted over the last 12 months.

S added that Plymouth Autism Spectrum service worked closely with Derriford who actively use hospital passports. However, it was not possible to store the information on the hospital system so they also used a 'reasonable adjustment form' which could be stored. It was the responsibility of the service user to take their hospital passport to appointments with them.

JR advised that RCHT held hospital passports for those users that had regular appointments, although the information was not available for doctors to download. A checklist was completed each time a patient visited which included whether they had a hospital passport, next of kin details etc.

CB asked what happened if someone went to hospital in an emergency. JR advised that if this was between Monday and Friday a member of the professional team would be called. The service was not yet available on the weekend.

AW added that as part of the autism pilot at Derriford, the service had been extended to 7 days a week. The pilot was due to end at the end of March but had been extended until June. The service was already covering 7 days a week for learning disabilities.

Use of Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Orders

Service users had expressed concern that restrictions in place due to the COVID-19 pandemic meant that DNACPR orders could be placed on them without them or their families being part of the decision making. The overriding message from the group was 'Our lives are valuable'. An example was also quoted whereby a member of the group with learning disabilities had been asked to make a DNACPR decision on behalf of a family member.

NM agreed that whilst this has been an ongoing issue the pandemic had particularly highlighted it.

Work had been done to make sure that decision makers were aware of their responsibilities under the Mental Health Capacity Act to consult with individuals. A learning disability must never be a factor in decision making about whether a person received treatment. If it was it would be a safeguarding issue and a breach of the law. Communications had been issued

<p>to GPs and work had been done at RCHT to audit cases.</p> <p>If an individual did not have capacity to be involved in the decision a best interest meeting must take place and be documented.</p> <p>If anyone had concerns they could contact NM or escalate the issue as a breach of the law.</p> <p>In Cornwall there had not been any examples found of somebody not receiving treatment or not being resuscitated just because they had a learning disability. If any cases were found they would require further investigation, which could involve the Police.</p> <p>Covid vaccinations</p> <p>Some confusion was expressed over the booking of appointments. Some group members were concerned at having to travel long distances to receive their vaccination, unaware that they could wait and receive their vaccination from their GP.</p> <p>Large centres did not make reasonable adjustments, allow extra time or provide easy read information for people with learning disabilities and/or autism, and supporters were not allowed to be present. There were however some positive comments about support from Learning Disability Liaison Nurses and how they had helped people through desensitisation and at appointments.</p> <p>The question was also raised as to whether somebody who did not take the vaccination would be prevented from attending day services in the future.</p> <p>Kate Mitchell, Programme Lead at NHS Kernow had responded to the feedback and said that it was unfortunate that invite letters were received before contact from GPs as it was always the intention that people with learning disabilities would be invited by their GP, who knew them.</p> <p>It exemplified why being on the learning disability register was so important. Anybody who was not on the register would not receive a local invite from their GP. Carers should also be registered as such with their GP.</p> <p>She also believed that people should be allowed to have a supporter with them and would follow that up with the appropriate teams.</p> <p>The decision whether to take the vaccination was down to the individual and should not affect access to services.</p> <p>NM added that vaccination invite letters from the NHS were sent out based on a national database of everyone in the UK and there was no way to identify those with learning disabilities as that information was held locally by GPs. A vaccination pathway now existed, which had been sent to all GPs and family carers.</p> <p>Making Disability Visible</p> <p>The group discussed what could be done to raise awareness in the community of learning disabilities and autism. The pandemic has meant that events like Blue Light Day have not been possible. The group would need to meet again to progress ideas and develop a plan.</p>	
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	<p>The following week was National Autism Awareness Week. Members were invited to share details of any activity or promotions they were undertaking with a view to partner agencies circulating information as widely as possible. Details could be sent to the Partnership Boards team at partnershipboards@healthwatchcornwall.co.uk.</p> <p>CB said that he had been shocked and disappointed by the prejudice he had experienced over the last few months and the lack of understanding towards people with disabilities in Cornwall.</p>	
4.	Working Age Adults Programme - Ann Smith, Cornwall Council	
	Ann Smith had been unable to attend the meeting.	AS to provide update.
5.	Update on LD and Autism Strategies - Vicki Allen and Nory Menneer	
	<p>NK provided an update from Mary Simpson, Chief Executive of Spectrum and Chair of the National Autism Alliance.</p> <p>She also sat on the inter party parliamentary group on autism, which had been tasked with formulating the new National Autism Strategy. The Strategy would provide Councils with legally binding guidance on what they must provide for people with Autism. It was anticipated that the draft Strategy would be approved in the next few months. The new national level Strategy would mean that Cornwall would be held to account for still not having a local level Strategy.</p> <p>Vicki Allen had been unable to attend the meeting. NM advised that the Autism Strategy for Cornwall would now be led solely by Cornwall Council. Previously, VA and NM had been leading to ensure a joint local authority and NHS approach. The Partnership Boards had not been made aware of the change prior to the meeting.</p> <p>There was no Cornwall and Isles of Scilly Learning Disability Strategy at the moment either. There was, however, an All-Age Strategy which was being prepared and included how accommodation, care and support was going to be taken forward by the Council. The NHS had a long-term plan for the next 5 years and NHS Kernow were being asked how it would achieve what was being asked for by the NHS.</p> <p>NK expressed her frustrations at the lack of progress on developing the strategies.</p> <p>TS updated that she would be working with Ann Smith and Commissioners to look at what the offer would be from the Council's operational/social work teams. She was aware that within the working age offer there would be provision for people with learning disabilities and autism and young people transitioning.</p> <p>The change in responsibility for writing Strategies for Cornwall was the decision to develop a 'whole offer' for people of working age.</p> <p>NM added that a learning disability strategy on its own would not address issues</p>	<p>PB team to liaise with TS & AS re progress.</p> <p>NM to</p>

	like accommodation, making it important to combine everything in an more encompassing way. It was agreed to discuss this in more detail at the next meeting and for NM to do a presentation on the NHS Long Term Plan.	present to June meeting.
6.	LeDeR Update - Nory Menneer	
	NM to email his update to the Partnership Boards team for circulation.	NM to email update to PB Team for circulation
7.	Update from the DIVAS	
	<p>The DIVAS had produced two short videos about International Women’s Day which had been circulated by the Partnership Boards team and were available on the Cornwall Council website.</p> <p>The following week was National Autism Awareness week. PC said that the DIVAS would be running an awareness campaign and they were keen to support and to help publicise any campaigns that other people/groups were doing. PC could be contacted at penni.charteress@womenscentrecornwall.org.uk.</p> <p>PC and Dina had met with Greater Manchester Women’s Support Alliance to support them in undertaking work similar to that of the DIVAS. They took part in research around Clare’s Law and its impact, recognising that women with learning disabilities and/or Autism were very under-represented. PC invited Board members to email her for more information or to get involved.</p> <p>The DIVAS were also recruiting for more members. If anybody would like more information they should email PC.</p> <p>NK highlighted the training that DIVAS had previously done with the Police and suggested that it would be helpful for FL to get in touch. FL welcomed the suggestion and undertook to make contact.</p>	
8.	Update from the CHAMPS	
	<p>SM said that the CHAMPS were currently on leave and due to return after Easter.</p> <p>SH updated that as part of the delivery of Healthy Cornwall they had been running some accessible healthy weight sessions over Zoom, WhatsApp, Teams and Facetime. They had done the same with ‘Fresh’ and recently been involved with some of the day centre virtual offers that Nick Matthews and the team had been delivering. They had also been running 1-1 wellbeing sessions with people to answer any queries or concerns.</p>	
9.	Update from Cornwall People First - Presentation	
	FH said that their Forums have been on hold during the pandemic although they have been doing phone calls and video calls with members. Saturday groups are also due to start again in April following the ‘rule of 6’ restrictions.	

	submitting a Freedom of Information may be helpful in the circumstances.	
10.	Any other business	
	<p>MM updated the meeting on a research project that is starting with autistic adults who have been assessed by Outlook South West, with a view to creating a peer support group. She would like to develop a public engagement group to review her proposal. The PB Team would share a summary of the project with the minutes of the meeting. Anybody interested in getting involved with the project could email mjm245@exeter.ac.uk.</p> <p>NK updated that the Carers Policy for Derriford was now in draft form and ready for comment. Anybody interested to see and comment on it could email partnershipboards@healthwatch.co.uk.</p> <p>NK added that the Mental Health Act is revised and is currently out for consultation. The consultation finishes on 21 April. It contains significant points that will affect people with learning disabilities and autism including detention in hospital and the reasons why people can be detained. Learning disability and Autism was not seen as a mental health diagnosis. You could not be detained under the Act just because of a learning disability or Autism without a mental illness. The PB Team would share the link to the gov.uk website, which included an Easy Read version of the document. If anybody needed support to access or comment on the document they could email partnershipboards@healthwatchcornwall.co.uk.</p> <p>CB mentioned the feature on BBC Spotlight recently regarding Nigel Marriott who had learning disabilities and Covid. He died alone in hospital last year. A fundraising page has been set up in his memory.</p>	<p>Circulate summary of project with minutes.</p> <p>PB Team to share link to Mental Health Act consultation</p>
11.	Future meetings	
	<p>Dates for 2021 meetings had been set in December 2020, when it was intended that the next round of meetings would revert back to separate Learning Disability and Autism Partnership Boards. Members were invited to email partnershipboards@healthwatchcornwall.co.uk with feedback regarding whether they would like to return to separate meetings or continue with a joint meeting.</p> <p>2021 scheduled meetings (all 10am on a Tuesday unless otherwise stated):</p> <ul style="list-style-type: none"> • Joint Learning Disability & Autism and Carers Service Users Event - 1 pm, 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 	<p>PB team to consider feedback and schedule meetings accordingly</p>

	<ul style="list-style-type: none">• 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	
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