

MEETING NOTES:	Meeting of the Autism Partnership Board
DATE:	Tuesday, 12 September 2023
LOCATION:	Trelawny Room, New County Hall, Truro and on Microsoft Teams

ATTENDANCE

Name	Position	Organisation
Councillor Sally Weedon (SW) (Chair)	Councillor	Cornwall Council
Mike Hooper (MH)	Partnership Boards Officer	Healthwatch Cornwall
Robert O'Leary (RO)	Partnership Boards Lived Experience Engagement Officer	Healthwatch Cornwall
Cheryl Bridges (CB)	Commissioning Manager	Cornwall Council
Christopher Burns (CB)	Service User and disability campaigner	
David Allkins (DA)	Autistic individual and Assistant Administrator for Assessments, Billings and Collections	Cornwall Council
David Burns (DB)	Autistic Individual and Community Promoter	Citizen Checkers and Healthwatch Cornwall
Debbie Rees	Clinical Review Officer	Cornwall and Isles of Scilly Integrated Care Board
Heather Davison (HD)	Autistic individual and parent carer	Divas and The Autistic Community of Cornwall
Julie Pape (JP)	Autistic individual	The CHAMPS
Karen Hooper (KH)	Head of Commissioning for LD, Autism and Mental Health	Cornwall Council
Kath Jarrett (KJ)	Self-advocate, Healthy Cornwall & CHAMPS	Cornwall Council
Kay Henry (KH)	Parent Carer and Director	Parent Carers Cornwall
Liz Cahill (LC)	Associate Director for Commissioning, Maternity, Children and Young People	NHS Cornwall and the Isles of Scilly ICB
Marie Ralph (MR)	Autistic individual and Parent Carer	The Autistic Community of Cornwall, Youth Art Connect and Cornwall Tourette's
Michelle Hooker (MHo)	Intermediate Public Health Practitioner Mental Health and Suicide Prevention	Public Health
Michelle Lobb (ML)	Parent Carer and Director	Parent Carers Cornwall
Nory Menneer (NM)	Commissioner for LD and Autism	Cornwall and Isles of Scilly Integrated Care Board
Paul Owen (PO)	Autistic individual and CHAMPS Team member	Cornwall Council
Penni Charteress (PC)	Mentor Coordinator/Community Engagement Worker	The Women's Centre Cornwall & Divas
Rebecca Jelbert (RJ)	Clinical Psychologist, Adult Autism Assessment Team	Cornwall Partnership NHS Foundation Trust
Sarah Keast (SK)	Commissioning Manager, Adult Care and Wellbeing	Cornwall Council

Steve Hillman (SH)	Health Improvement Practitioner, High Risk Groups and CHAMPs	Cornwall Council
Stuart Ralphson (SR)	Autistic individual and CHAMPs Team member	Cornwall Council
Susan Joseph (SJ)	Interim Strategic Commissioner for LD and Autism	Cornwall Council

APOLOGIES

Name	Position	Organisation
Alison Bulman		Cornwall Council
Alison Short	Advocacy Coordinator / Independent Advocate	The Advocacy People
Andrew Gray	Autistic Individual	
Anna Ingleby-Oddy	Housing Manager	United Response Cornwall
Clive Gaylard	Service Manager, Proper Job	Cornwall Council
Deanne Hill	Patient Engagement Lead	South Western Ambulance Service NHS Foundation Trust
Debbie Rees	Clinical Review Officer	Cornwall and Isles of Scilly Integrated Care Board
Dina Holder	Community Engagement Manager	The Women's Centre Cornwall & Divas
Donna Darby	Director	Calton House Ltd
Fliss Hedge	Operational Lead	Cornwall People First
Sgt Flo Linscott	Diverse Communities Lead	Devon and Cornwall Police
Jane Rees	Manager of the Learning Disability and Autism Team	Royal Cornwall Hospital NHS Trust
Julie Atwell-Cook	County Parenting Advisor for Early Help, Together for Families	Cornwall Council
Julia Wildfire-Roberts	Project Manager, Recovery College Cornwall, HC Director and autistic individual	Pentreath and Healthwatch Cornwall
Kate Alcock	Head of Commissioning – Older People and Carers	Cornwall Council
Lizzie Denison	Opportunity Coach and Co-Production Lead, Proper Job	Cornwall Council
Tigger Pritchard	NAS Committee Member, Autistic and Neurodivergent individual, national and international speaker on advocacy and neurodivergence rights	NAS Cornwall and The Autistic Community of Cornwall

ACTIONS

Action	Responsible	Status
ER hospital letters.	JR	Ongoing. Not yet signed off
Police Interactions with Neurodivergent People. Board attendance at Oct CRG. Police report to Board in Dec.	PB Team / MR / DH /TB	Ongoing. Item on 12/12/23 agenda.

Action	Responsible	Status
DWP Service Users Group – Update on actions	AC / JC	Ongoing. Verbal update on actions taken by the DWP in response to the recommendations of the Group to 12/12/23 meeting.
Accessibility and integration of Mental Health services for neurodivergent individuals.	PB / RJ	Ongoing. PB Team to liaise with RJ to determine future information and input.
LeDeR updates.	PB Team / SS	Ongoing. Board to receive information as timely and between meetings via email as it becomes available.
KH to link ML with appropriate Blue Badge officer for consideration outside of the Board.	KH / ML	Ongoing.
Source appropriate GP representation for the Board.	PB Team	Ongoing.
Circulate Draft “Celebrating Neurodiversity” Strategy for members’ comments	LC / PB Team	Complete.
Provide details of statutory obligations within delivery of Better Lives Strategy.	TBC	On hold due to review of rollout of BLS.
Further information on how to access the services of The Advocacy People. Provide details of statutory obligations regarding advocacy support.	PN / AS	To be scheduled.
Convert Direct Payments information into easy read for circulation.	AS / CG	On hold due to review of Policy.

Item	What was discussed	Action
1.	Welcome, introductions and apologies	
	<p>The Chair welcomed everyone and advised that the meeting was being recorded for minute taking purposes.</p> <p>Apologies received are detailed above.</p> <p>The Chair invited everyone present to introduce themselves.</p>	
2.	Minutes of the meeting held on 20 June 2023 and actions from previous meetings	
	<p>The Chair invited any issues from the minutes of the last meeting to be raised.</p> <p>No issues were raised and they were therefore accepted as a true record.</p> <p>MH updated on actions from previous meetings:</p> <ul style="list-style-type: none"> <i>The use of Easy Read Hospital Appointment Letters – Jane Rees informed us that these have not yet been signed off as lots of IT issues have arisen.</i> 	

<ul style="list-style-type: none">• <i>We've been liaising with Teresa Berridge, the Equality Diversity & Human Rights Officer at the Police and Robert will be attending their Community Reference Group meeting on 19th October. At that meeting the Force's Learning & Development Department will be discussing its work to scope its training and resources that are available to officers/staff in regard to neurodiversity. We have asked that the Board are able to input into that by agreeing today on the key issues affecting Police interactions with neurodivergent people. Marie Ralph will lead on that item later on in the agenda.</i>• <i>We got in touch with Jane Rees at RCHT regarding SWAST crews not having access to information held on Hospital Passports. Jane said that passports should be kept by the individual, they aren't meant to be kept on electronic systems as they often change for the individual and should be updated regularly.</i> <p><i>Historically, SWAST and the police will not upload these documents to their systems, as they need to then be updated and owned by someone and they say they don't have staff or systems that can facilitate this, so it is down to the individual to have copies of them for them to read. This is not unique to hospital passports it the same for all other services like CAMHS , Dementia passports, Communication passports etc. We have had many discussions with SWAST and the police over the years and the answer is always no.</i></p> <ul style="list-style-type: none">• <i>We've spoken previously about the possibility of utilising the Hospital Passport App in lieu of there being an autism alert card. Sgt Flo Linscott is going to meet with PC Jason Howard for an update on this.</i> <p><i>MH suggested that the above two issues could be included as suggestions if the Board agrees to write to the Police?</i></p> <p><i>MR added that the Autistic Community of Cornwall (ACC) had set up an Autism Alert Card. They contained all necessary information about the individual, including emergency contacts, and were available free of charge.</i></p> <ul style="list-style-type: none">• <i>At the last meeting it was agreed that the Housing Options Manager be asked to join us for a question and answer session. Unfortunately, we didn't receive any questions so it hasn't been included on the agenda. However, Kevin Beveridge, I believe, will be updating us on the Making Good Change Happen work at our next meeting and Sarah Keast is here today to tell us about the new Supported and Specialist Housing Strategy.</i>• <i>Our DWP Service Users Group met again at the end of June and our DWP reps will be updating us on work they have undertaken as a result of that at our next meeting.</i> <p><i>PO, a member of the group, expressed his frustration with the DWP</i></p>	<p>RO / MR / DH</p> <p>AC / JC</p>
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representatives present at that meeting, stating that he thought that they were disingenuous in their responses.

- *We spoke previously about the possibility of an audit of the accessibility of mental health services for neurodivergent individuals.*

RJ provided background to the integration of Adult Assessment Team into the Cornwall Foundation Trust and how that had provided the opportunity link in with Mental Health colleagues around the difficulties faced by autistic people in accessing mental health services locally. It was know that autistic people were more vulnerable to poor mental health and the Government's latest Suicide Prevention Strategy had identified autistic people as an 'at risk group'. The teams had a real will to work together to ensure that services overcome previous issues around capacity, lack of training and lack of knowledge and do better.

A three-step training programme with the ACC had begun, bringing lived experience to the whole mental health team. Step 2 would involve more focused training for mental health colleagues, helping them to identify and assess autism when individuals are accessing services and autism is being queried alongside mental health presentation. Step 3 would look at the Health Education England national autism training programme. That included theories of setting-specific training, including one in relation to community health settings. It was hoped that could eventually be rolled out at a local level.

It was also necessary to ensure robust supervision consultation mechanisms around the newly trained colleagues. As part of that there was a newly created role for an Advanced Clinical Practitioner specialising in autism. It was a trainee role embedded within Community Mental Health systems that provided another level of support for those colleagues. Accessible communications, tailored to the individual, were a key element. There was also a new sensory expert within the Assessment team. Whilst there was still a long way to go, connections were being made and people all across the Trust were giving increased consideration to neurodiversity.

MR thanked RJ and her team for engaging with the ACC in a collaborative, rather than a consultative, way. She added that there was also a trial of a post-diagnostic support group. RJ said that the service had only ever been contracted to provide assessment and diagnostic support but had always recognised the need for post-diagnostic support.

DA was concerned about the lack of post-diagnostic support and asked if depression and/or poor self-image were recognised issues. As a minimum, were people given leaflets about where to seek help? RJ said that had never been a service that they were contracted to deliver so tracking such matters had been difficult. In lieu of that, they had looked at national evaluations of specialist autism teams and some of those had stated that services that do not have post-diagnostic follow-up offers do

	<p>see negative impacts on individuals. The team had always signposted to mainstream information but autism-specific information was necessary. MR added that teenagers were often the worst effected.</p> <p>The Partnership Boards team would liaise with RJ to determine future information for the Board.</p> <p>CB agreed said that there was great need for increased help within all aspects of life for autistic individuals in Cornwall. Currently, there wasn't a Social Prescriber covering the Torpoint area and people were getting support from outside of the county to complete PIP forms. It could be that support was concentrated in and around Truro as there simply wasn't support for many towns beyond the A30. RO, who had previously been a Social Prescriber in another area, invited CB to connect with him outside of the meeting.</p> <ul style="list-style-type: none"> • <i>RO and MH had met with Sara Sanders, the new LeDeR lead. The Board agreed to ensure that it always have the opportunity to receive timely information on LeDeR, a standing invite be extended to Sara to join meetings as timely and also for members to receive information via email as it becomes available.</i> • <i>Issues with the Blue Badge process – KH undertook to share a contact with whom issues could be discussed with ML outside of the meeting.</i> • <i>At a previous meeting the Board discussed how considering health inequalities is difficult without GP representation. Phillip Hanscombe and Caroline Finlayson had offered to see if they could identify a GP representative for the Board but no-one put themselves forward. The Board agreed that the Partnership Board team write to the ICB to formally request one.</i> • <i>We asked for clarification of what the statutory obligations are within the delivery of the Better Lives Strategy. KH stated that clarification would be provided along with information on how they would be implemented at a future meeting.</i> • <i>Conversion of the Direct Payments Policy into easy read – this is on hold as the Policy is currently under review.</i> 	<p>PB Team / RJ</p> <p>SS</p> <p>KH</p> <p>PB Team</p>
<p>3. Updates from Members</p>		
	<p>Chris Burns</p> <p>CB reported the awareness work that he and SR had been doing for the Torpoint Diverse Advisory Panel.</p> <p>SR had read 'This is Me!' by George Webster to an audience of parent carers</p>	

	<p>and children at Torpoint Library. It had been inspirational and asked that Cornwall Council roll it out at libraries across the county. SH undertook to feed the suggestion back to Shelagh Mitchell, CHAMPS Manager, to progress. SR added that he had enjoyed the event and feedback had been very positive.</p> <p><i>Following the meeting, the PB Team shared disability awareness artwork created by CB across the Partnership Boards and liaised with the Library Service to request that it be displayed across the county.</i></p>	
<p>4.</p>	<p>Break</p>	
	<p>The Board took a 10 minute comfort break.</p>	
<p>5.</p>	<p>Young Persons Autism Strategy for Cornwall</p>	
	<p>LC opened by clarifying that it was a Neurodiversity Strategy and apologised for having neither the Strategy nor her presentation available in easy read. LC said that she would send the presentation through to attach to these minutes as an Appendix (<i>these were not received</i>).</p> <p>The main points made were as follows:</p> <ul style="list-style-type: none"> • There was a recognition that people felt strongly about the differences between the terms ‘neurodiversity’ and ‘neurodivergence’. An exercise was being undertaken to decide where in the Strategy it would be more appropriate to use the latter. • The four key elements were: <ul style="list-style-type: none"> - Cultural change with a focus on outcomes; - Diversity not deficits; - Focus on “need” not just gaining a diagnosis; and - Earlier help. • Five ambitions: <ul style="list-style-type: none"> - Develop a multi-agency offer of early support to improve children’s outcomes and make reasonable adaptations to their neurodiversity, regardless of diagnosis; - Integrate the pathways for all specialist assessments, including diagnosis; - Develop specialist intervention where needed for those with neurodiversity who have significant challenges, including during developmental transitions throughout childhood into adulthood; - Develop a workforce that can adapt and respond appropriately to young people with neurodiverse needs across all services; - Empower education settings, training providers and employers to ensure children and young people with neurodiverse needs can achieve and feel they belong. • A recognition that there was a wide range of neurodiverse diagnoses 	

	<p>and a need to improve identification of individuals needing further assessment.</p> <ul style="list-style-type: none"> • The impact of lifestyles and experiences. Masking seemed to be particularly prevalent in late-presenting girls. • The need to streamline assessments and provide post-diagnostic support for certain diagnoses. • A “Neurodiversity Hub” was in development. Members were asked to assist as individuals in any way they could. • There were many elements of NICE guidance that the current pathway did not support. • Referral rates had increased from around 70 a month to 200. Growing the Assessment Team to meet that rate had not been possible. Even if funds were available, recruitment would be very difficult. • The new pathway tool designed to support structured conversations had been developed and proved successful in Portsmouth. • Initial actions had been taken to improve assessment process and specialist support. <p>LC invited questions from the Board.</p> <p>MR asked for clarification on the focus of the Strategy. LC replied that it was focused on the identification of conditions through the presenting needs. MR sought further clarity as to whether the focus was solely neurodevelopmental conditions or on the whole neurodiversity pathway. LC confirmed it was the latter.</p> <p>MR asked how the ICB intended to educate educators to be able to use the tool provided properly. LC said that the tool was a guided conversation that helped to identify individual strengths and challenges, not a diagnostic tool. By having something that everyone used, teams would learn together and have access to advice and information. Also, the website would really help parent carers and it would be great for the ACC to provide the voice of lived experience to develop it.</p> <p>MH asked that MR and LC continue the conversation outside of the meeting and that any issues relevant to the work of the Board be reported to the next meeting.</p> <p>MH asked where the draft Strategy could be accessed with a view to Board members being able to comment on it prior to agreement. LC shared the document with the PB team and it was circulated to Board members for comment following the meeting. LC had advised that</p>	<p>LC / PB Team</p>
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	<p>comments be sent direct to her at the earliest opportunity as the Strategy would be considered by the Council's Cabinet in December.</p> <p>MH asked if the Strategy covered young people up to 25 years old. LC replied that whilst the principals were potentially up to 25, the pathway wasn't as most services were configured up to 19. Further work would be required to bring the adult and the children's work together. SJ, who was leading on the development of the Adult Strategy, said that she would connect with LC to ensure that the two strategies interlinked.</p> <p>KH said that there needed to be transparency around who would be providing training. She also offered to circulate the draft Strategy for comment through PCC networks. LC encouraged circulation and said that "training for trainers" was planned. Confirmation of training providers would be confirmed following that.</p> <p>RJ referenced the transitioning population – those contracted to be seen by CFT's adult service between the ages of 16-18 but also adult services – and stated the importance of providing clarity for referrers. LC agreed that conversations were needed. Timelines for that were currently unclear.</p>	
<p>6.</p>	<p>Cornwall Supported and Specialist Housing Strategy 2023</p>	
	<p>SK gave a presentation on the development of the Cornwall Supported and Specialist Housing Strategy, as circulated with the agenda (click here).</p> <p>The strategy was still being worked on ahead of being considered by the Council's Cabinet in November.</p> <p>SK invited members to email her with questions and comments direct or raise them now.</p> <p>The Chair asked how the Council would manage the increased funding streams. SK said that the capital side of developments (building schemes) would usually be funded by housing providers themselves. There shouldn't need to be an increase in funding from the Council. It could be that savings would be made in residential care as that was more expensive than caring for people in their own homes.</p> <p>RO asked if safeguards were in place to prevent providers from increasing the cost of rent. SK said that 'affordable rent' would be in place, so capped at 80% of current market value. Supported Housing schemes were more expensive to run as, ie, the cost of managing communal areas would be added to service charges. However, Enhanced Housing Benefit should cover the difference. Also, legislation passed this year, to take effect in 2025, would give local authorities a duty to regulate supported</p>	

	<p>housing provision both in terms of cost and the quality of support received by renters.</p> <p>PO asked if local authorities would have the power to impose caps. SK said that would not be the case but they could say that they would not pay housing providers for people to live there anymore. PO continued, asking how “affordable” was determined, especially as the cost of living continued to increase. SK agreed with the sentiment but the definition was nationally defined.</p> <p>PC asked if the Strategy would have provision for ensuring that staff would be trained to identify signs of abuse or exploitation either within the facility or from outside. SK replied that not much was known about the new legislation but local authorities would be given responsibilities for supported housing, including ensuring quality. Adult Social Care’s Quality Assurance Team would visit to ensure that standards were upheld and care needs met. Training was included within those measures. As regulated housing providers, they would also be subject to CQC inspections.</p> <p>HD wanted to know how people on benefits could afford to live in such schemes and what measures would be in place to ensure the safety of residents. SK said that such schemes already existed and that Enhanced Housing Benefit would be available. As support providers, they would have a support contract with the Council that would be monitored by the Quality Assurance Team. Regular meetings would be held with providers to ensure that they are meeting the terms of the contract.</p>	
<p>7.</p>	<p>Police Interactions with Neurodivergent People</p>	
	<p>MH opened by referencing many previous conversations had by the Board around Police interactions with neurodivergent individuals, few of which had been positive.</p> <p>At the last meeting of the Board it had been agreed that the PB Team liaise with MR and Dina Holder as to how best to facilitate a discussion with the Police and the information that needed to be presented to them. Having met, it had been agreed with Teresa Berridge, Equality, Diversity & Human Rights Officer, Devon and Cornwall Police that a report be submitted to the Police’s Community Reference Group (CRG) on 19th October, a meeting that its training team would be attending.</p> <p>It was added that the report did not only focus on negatives, it also highlighted areas of good practice and detailed what had and hadn’t worked for different groups.</p> <p>PC reported that in addition to the information contained within the report, The Women’s Centre Cornwall had been working with Easy Read</p>	

	<p>UK to develop an accessible means of reporting to the Police. Once available, that could be shared with the Board.</p> <p>A report had been written by MR and DH and circulated with the agenda (click here). MR added that she had talked with various groups online and in person to learn more of peoples experiences. She also provided further background of conversations that she'd had with the Police around better ways of working to ensure that people in distress were not handled in the same way as criminals might be. Training around de-escalation and low-arousal models would be beneficial for a whole host of marginalised groups. There also needed to be talks around intersectionality and taking 'low-level' and disability hate incidents more seriously.</p> <p>RO asked if local training options would be investigated or if a national approach was preferred. MR said that the Police were using a national organisation called Creased Puddle, which was run by neurodivergent people. However, the level of uptake was down to individual Forces to decide. The ACC would be contacting Creased Puddle to discuss how they could align with them to make local services better.</p> <p>PC said that there was national training available to Police Forces through Operation Soteria Bluestone. The Divas had inputted and created training materials for them but it was down to individual Forces or even individual officers to pursue the offer as it was not mandatory.</p> <p>MH said that Teresa Berridge had committed to attending the Board's December meeting, along with a member of the Force's training team, to address issues raised and the responses of the Police.</p> <p>MH noted that the report covered all existing actions requested of the Police by the Board. The Board agreed that the report be submitted to the CRG for consideration and response, subject to the opportunity being extended to other groups to contribute, specifically Parent Carers Cornwall, The CHAMPs, CAAP and the Parents of Disabled Children Network.</p> <p>CBr said that the Local Criminal Justice Board was chaired by the Police and Crime Commissioner and a sub-group of that was The Dignity of Women Within the Criminal Justice System. The Board agreed that the report and eventual outcomes received be shared with that group.</p>	
<p>8.</p>	<p>Any other business</p>	
	<p>Adult Autism Strategy</p> <p>SJ reported that she was forming a working group of professionals and people with lived experience to help to draft the Adult Autism Strategy.</p>	

	<p>Meetings would focus on the identified priorities, with the first meeting looking at Improving Awareness and Improved Support.</p> <p>Members were invited to put themselves forward or make recommendations of people to join the Working Group.</p> <p>The PB team circulated an invite to all Board members following the meeting.</p>	
<p>9.</p>	<p>Future meetings</p>	
	<p>The next meeting would be held at 10:30am on Tuesday, 12 December 2023 in the Trelawny Room, New County Hall, Truro and on Microsoft Teams.</p>	