

MEETING NOTES:	Meeting of the Autism Partnership Board
DATE:	Tuesday 22 June 2021
LOCATION:	Via Teams

ATTENDANCE

Name	Position	Organisation
Mike Hooper (MH)	Partnership Boards Officer	Healthwatch Cornwall
Anne Oliver (AO)	Business Support Manager	Healthwatch Cornwall
Anna Passmore (AP)	Patient Experience Manager	Cornwall Partnership NHS Foundation Trust
Anne Bowdler (AB)	Primary Care Liaison Nurse for Adults with a Learning Disability	Cornwall Partnership NHS Foundation Trust
Andrew Gray (AG)	Self Advocate and Service User	N/A
Ann Smith (AS)	Social Worker, Head of Commissioning for LD, Autism and Mental Health	Cornwall Council
Christopher Burns (CB)	Self Advocate and Service User	N/A
Darren Moyle (DM)	Behaviour Specialist	Spectrum
David Allkins (DA)	Revenue and Benefits Admin Assistant and Self Advocate	Cornwall Council
Sgt Flo Linscott (FL)	Diverse Communities Team rep	Devon and Cornwall Police
Nory Menneer (NM)	Clinical Lead and Learning Disabilities Commissioner	NHS Kernow Clinical Commissioning Group
Rebecca Arthur (RA)	Employment Support Officer Employability Cornwall, Adult Social Care	Cornwall Council
Rebecca Jelbert (RJ)	Clinical Psychologist, Adult Aspergers Assessment Team	Cornwall Partnership NHS Foundation Trust
Sarah Williams (SWi)	Family member and carer of an adult with Autism	N/A
Sandra Ward (SWa)	Parent Carers Cornwall and Chair of Carers Partnership Board	Parent Carers Cornwall
Sarah Cuignet (SC)	Employment Support Officer Employability Cornwall, Adult Social Care	Cornwall Council
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 Sanford (TS)	Learning Disability, Autism and Transitions Manager for Working Age Adults	Cornwall Council
Vicki Allen (VA)	Adult Social Care Commissioning Manager with responsibility for Learning Disability and Autism	Cornwall Council
Vicky Coxhead (VC)	Volunteer	National Autistic Society Cornwall

APOLOGIES

Name	Position	Organisation
Nuala Kiely	Partnership Boards Officer	Healthwatch Cornwall
Councillor Andy Virr	Portfolio Holder for Adult Social Care	Cornwall Council
Jane Rees	Learning Disability and Autism Team Manager	Royal Cornwall Hospital NHS Trust
Michelle Lobb	Carer	Patient Carers Council
Paula Volkner	Transforming Care Plan Project Manager	NHS Kernow Clinical Commissioning Group
Tigger Pritchard	Autism and PDA Advocate, Consultant & Trainer	National Autistic Society Cornwall
CHAMPS Team	CHAMPS	Cornwall Council

ACTIONS

Action	Responsible	Status
Share presentation to LDPB on the NHS Long Term Plan with APB members.	NM / MH	Incomplete.
Liaise to ensure timely updates on progress of Autism Strategy.	AS / TS / PB Team	Ongoing. MH met AS & TS in May. Update to 22 June 2021 APB. Update due at Sept 2021 APB.
Convert Direct Payments information into easy read, for circulation.	NK	Ongoing.

Item	What was discussed	Action
1.	Welcome, introductions and apologies	
	MH welcomed everyone to the meeting and introduced AO, who would be taking the minutes. He apologised that Nuala Kiely was unable to attend. Everyone would have an opportunity to introduce themselves later in the meeting and to share any feedback or updates.	
2.	Minutes of the Joint Meeting of the Autism & Learning Disability Partnership Boards held on 23 March 2021.	
	<p>The minutes of the Joint Meeting of the Autism & Learning Disability Partnership Boards held on 23 March 2021 were confirmed as a true record.</p> <p>Actions from the meeting:</p> <ul style="list-style-type: none"> Information on the re-opening of Day Services and respite was e-mailed by the PB team on 6 April 2021. This was in advance of the announcement to delay lockdown easing originally planned for 21 June 2021. An update was from AS was on the agenda. 	

	<ul style="list-style-type: none"> • Learning Disability Programme and LeDeR updates had been circulated with the agenda for the LD Partnership Board meeting held on 8 June 2021. • Conversion of Direct Payments information into easy read had been delayed. • Presentation to LDPB on the NHS Long Term Plan would be shared with APB members. • Feedback from LDPB and APB members had shown a clear preference to return to individual meetings rather than the joint meetings that had been held throughout the pandemic due to overlapping issues for consideration. 	<p>NM to email to MH to share.</p>
<p>3.</p>	<p>Introduction and update from members</p>	
	<p>MH invited those present to introduce themselves and to give a short update on the work of their organisation or their experiences since the Board last met at the joint meeting held in March.</p> <p>VC was a new attendee, she was a volunteer for the National Autistic Society, Cornwall Branch, and was attending in place of TP.</p> <p>NM reported that a recruitment campaign was underway for the Autism Crisis Service. The Leadership Programme was changing to include Autism without a Learning Disability. There had been concerns over access for the Covid-19 vaccination programme and he thanked AB for her ongoing work on the matter.</p> <p>SWa reported that Parent Carers Cornwall were trying to restart face to face meetings, recognising that mental health and isolation were real issues affecting carers at the moment.</p> <p>FL from the Devon & Cornwall Police Diverse Communities Team was attending to listen and learn and hoped to be able to feedback at the next meeting on preparations for next year's Blue Light event.</p> <p>AG shared that he had been preparing a Functioning Maths Skills training session, to take place at All Saints Community Centre, which would be one to one training to start with. The course would be free but there would be a £2 charge for refreshments, sessions were planned to be 2 hours with a mixture of tuition and games. Anyone interested should e-mail partnershipboards@healthwatchcornwall.co.uk who would relay their message to AG.</p> <p>AP said that the Patient Leadership Programme at CFT was open to applications from all. Applicants would be assessed to see how they could be supported. Current recruitment was due to close but recruitment for a new cohort would start shortly. AP also mentioned Care Opinion, which was a platform where people could give feedback about any service provided by CFT. The feedback went straight to the provider for response. CFT were upgrading to a higher platform to enable two way dialogue and to inform on what had changed as a result of people having their say.</p> <p>CB highlighted a film recently released called 'The Reason I Jump', based on the book by Naoki Higashida, exploring the experience of non-speaking autistic people around the world. Unfortunately, no cinemas in Cornwall were showing it, with the nearest viewings in Exeter and Totnes. He also raised an issue over</p>	

	<p>an inadequate CQC rating in aspects of his local GP service around long-term disability and mental health. He wondered if there was a process to follow up actions required by the CQC. NM and AO both undertook to liaise with CB outside of the meeting.</p> <p>Cllr Andy Virr, the new Portfolio Holder for Adults and Public Health, Cornwall Council, had informed MH that he hoped to be able to join some future meetings.</p>	
<p>4.</p>	<p>Feedback from the Learning Disability and Autism Service Users and Carers Event on 1 June 2021</p>	
	<p>MH fed back from the recent Learning Disability, Autism and Carers Service Users Event.</p> <p>Update on Day Services</p> <p>MH had sent the following summary of the discussion to AS and TS on 3 June:</p> <p><i>Helen Cahalane from Cornwall Council had said that a letter would be sent to service users very soon. There were more service users in the West but more people in the East had received some sort of service since 12 April. That could be partly because of Covid rules. In the East, 93 people had received a service and 27 people had received no service at all. In the West, 70 people had received a service and 78 had received no service at all.</i></p> <p><i>Members of the group were frustrated as private day services had reopened successfully whilst Council services remained very restricted. They wanted to know how private services were able to meet government guidelines on bubbling, social distancing etc but the Council could not.</i></p> <p><i>A member cited one day service that was only able to take up to 15 people. Users had varying ages and degrees of disability and autism and they were finding it very hard to reintegrate. They were having to start again with all of their practices such as relationships, tolerance, being calm etc, and that was making it very difficult for them to get on with their peers. It was very worrying that numbers showed that some people were not returning, possibly due to mental health issues on top of their pre-existing conditions, and indicated that people could not cope having had such limited support for such a prolonged period.</i></p> <p><i>Helen had said that the people were prioritised for a service through a fair, nationally recognised system. A member said that the Council used a traffic light system - those with highest need were identified with a red light and they were prioritised to receive services.</i></p> <p><i>A member asked what guidance the Council were following for the reopening of day care services and Mike posted this link - How to approach re-opening day care services (scie.org.uk).</i></p> <p><i>As people had cared for their loved ones at home for 15 months, it was thought that the Council must have reserves of unspent monies. Was that the case and, if so, what would that money be used for?</i></p> <p><i>A member said that she understood that not all service users received the last letter that was sent out on 6 April.</i></p>	

Often only 1-2 hours of outreach was offered a week. Everyone agreed that service users desperately needed the return of day services - the most vulnerable people in society were being let down by the Council. A breakdown of services offered was requested.

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

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

A member questioned why the Council had changed their policy on allowing people to buy laptops with their direct payments. Communication was a basic need and without that service users were being made to feel more vulnerable and isolated while day services were shut. A member suggested that Outreach could provide tablets.

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

MH asked that AS address the issues raised in her update later in the meeting.

Autism Strategy

Attendees had been keen to ensure that service users were fully involved in the development of both the Autism Strategy and the Learning Disability Strategy.

Making Disability Visible

The service user group had discussed a scheme to help make disability more visible in the community. The Divas and Cornwall People First were mentioned as possibly being interested in helping to progress.

Hospital Passports

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

It was agreed that a Learning Disability Liaison Nurse to come to a future meeting to discuss Hospital Passports with the group.

A member was currently working with colleagues at Treliske on medical cards and hospital passports and they were due to meet again soon. She also hoped to involve Derriford.

SWa said that she had written up about Hospital Passports in the Parent Carers Cornwall newsletter and had received good feedback from patients at both Derriford and Treliske.

	<p>Support for the Continuation of the Liaison Service for People with Autism provided by the Autism service at Derriford</p> <p>The service was funded until 20 June. The group had agreed that MH email the lead partners to express support for the continuation of the service. NM confirmed that email had been received and encouraged others to continue write with their support. Due to this meeting being held after 20 June, MH had previously circulated information to all Board members to enable individuals to express their support. NM added that there was also a possibility of funding through NHS England</p> <p>Future Meetings</p> <p>TH wanted to feedback her view that it was much more pleasant to meet via Zoom or Teams than in person. Everyone took their turn, you could join without leaving home, therefore eliminating the need to prepare to have to go on a journey, nobody got shouted over or overwhelmed and that empowered people to be more able to contribute.</p>	
<p>5.</p>	<p>Update on Day Services</p>	
	<p>AS explained that she was now the senior manager for short break provision, day service provision and employment provision within Cornwall Council. Due to the Government delay to relaxing Covid-19 lockdown restrictions, the Council was having to re-open in line with the updated guidance for social distancing measures and testing. That impacted on the numbers that could be supported.</p> <p>The initial focus would be on individuals living with family carers and Shared Lives. They would then look at individuals who used to attend day services and discuss if alternative activities that had been found during lockdown would be preferable and if people would like an alternative offer. The aim was to speak to everyone individually to see what services would best meet the needs of those who required 24 hour support.</p> <p>The same process was being undertaken for short breaks.</p> <p>MH asked for clarification as the letter on reopening had gone out prior to the Government delay to relaxing lockdown rules. AS admitted that the timing of the letter had not been helpful and confirmed that it was being followed up individual calls to service users.</p> <p>SWa asked why private day centres were able to operate when Council run ones couldn't. AS said that was mainly because of the buildings the Council used - they were struggling to meet the Government guidance because of issues such as sharing space with other provision and the layout of buildings - Newquay Day Service was an example. The Council was looking at alternative spaces. CB asked if the Council could refer people to the private sector. AS said that the Council were looking at other offers but wouldn't make any changes until they had engaged with service users. Plans would then have to be put to colleagues within the Council for any upgrading of existing buildings or use of alternative buildings. She emphasised any plans would be driven by the people who used the service.</p> <p>MH asked about timescales - AS responded that her initial report was due by</p>	

	<p>the end of June but she had no timescale for change, which would be part of a wider strategy that would have to go through the Council’s governance process. She noted the need to be ready for proposals by April 1922 at the launch of the All Age Strategy.</p>	
<p>6.</p>	<p>Autism Strategy</p>	
	<p>AS shared a visual display of where the Autism Strategy would sit within the wider work of Adult Social Care (ASC) called “Delivering Better Care”, which encompassed all the services provided both singly and in partnership with other departments of the Council and health colleagues. The Strategy for Better Lives, which AS was leading on, sat within that and included under 65s with LD, autism, mental health and other needs. The principles across workstreams focused on inclusivity and included transition (preparation for adulthood) for 16+. There would also be greater focus on prevention, health and wellbeing, managing day to day and ensuring opportunities for individuals.</p> <p>There was no wish to pigeon hole neurodiversity as all individuals were recognised as unique and had individual needs. An example was given of how the Council was starting to look at how services were impacted by neurodiversity - it was employing specialist architects to design spaces that recognised and didn’t adversely affect needs stemming from neurodiversity.</p> <p>AS confirmed there was a legal requirement for an Autism Strategy and ASC were working with Together for Families on ensuring that it covered all ages - she was especially mindful of transition difficulties. They were also working with health and would seek views and input throughout the journey. AS stated the importance of involving the Board in the development of the Strategies.</p> <p>There was an existing Mental Health Strategy so it needed to be clear how the Autism Strategy contributed to that for improved mental health outcomes, similarly with the Learning Disability Strategy. In addition, there was a Complex Needs Strategy being developed by Community Safety for those with drug and/or alcohol or domestic violence issues, which didn’t necessarily require ASC involvement but they would be working together.</p> <p>MH had met with AS and TS and all had agreed on the importance of involving the Board at the earliest opportunity rather than waiting for an Autism Strategy to be drafted before inviting comments. A co-design and engagement plan was being developed to start the conversation immediately and to continue it all the way through the process. AS wanted individuals to be involved in the design process and to help to define desired outcomes.</p> <p>The Strategy would include:</p> <ul style="list-style-type: none"> • housing with care and support - feedback already received had included more home ownership, more assured tenancies, more flexible service options and moving away from residential models of care to less restrictive options; • day activities - which could include employment or other meaningful activity - what does a good day look like?; and • different forms of short breaks - as opposed to a focus on respite. <p>The update was generally welcomed by members of the Board.</p> <p>TS asked AS and NM about the plan around early intervention following diagnosis, when people may already be in crisis with their mental health. AS</p>	

said there was no fixed way yet for developing the Strategy and it was important to capture issues like that. She was really interested in the Plymouth service and wanted to find out more, which was also why she wanted to work more jointly with Together with Families to support people from an earlier age. RJ seconded that approach.

The discussion turned to how to capture feedback and information. Plans and surveys were being drafted but AS acknowledged there was a lot to do to capture individual experiences and that was why there would be an Engagement and Co-design Strategy, to bring all of the conversations together.

MH commented on the huge amount of work required in a short space of time and suggested that Strategies would need to be in final draft form by the end of the year if they were to be rolled out by April 2022. AS confirmed that was the case. Strategies would be launched in April but the work in earnest would then begin - to implement the Strategies, monitor their implementation and effect change. It was now essential to ensure that plans and surveys were developed and undertaken in as inclusive a manner as possible and in line with Government Covid-19 guidelines. Capturing lived experiences was also key.

RJ highlighted the National Institute for Health Research (NIHR) national research on different diagnostic and Autism services. It detailed what had been helpful, what hadn't and what had been missing from different forms of service. It also included the impact of diagnosis with and without post-diagnostic support. That report would be a good foundation from which to build up the health side of the Autism Strategy. Also, at a local level, feedback from clients had been collected for many years on what they felt post-diagnostic provision should look like, should it become available. Similar themes had emerged repeatedly, which could be fed in to the health side of the work. Currently, there were really big gaps that needed to be filled. AS agreed, saying that the work was not starting from scratch and that it was vital to include views that had already been gathered.

TH asked if the Cornwall Independent Autism Network could feed into the work and AS said she was happy for everyone to get in contact or for her to be invited to talk to groups. AS confirmed that she would be happy to meet with Tigger Pritchard of the National Autistic Society (Cornwall branch) and associates to discuss how the work would link in with the 'Not Enough' campaign.

CB said that the pandemic had resulted in a lot of unplanned expense but early intervention and training should be happening now - where would the money come from? AS acknowledged that ASC was already spending more than it received but she was making the case for change, pushing the view that prevention and support saved money in the long run. CB emphasised that it had to be sustainable. AS said that there were organisations, some international, that were really good at ensuring that and she wanted to work with them to remove barriers, for example, benefits being affected. Such expertise was essential.

VA acknowledged there was a lot of work to do but saw it as a really exciting joint working opportunity and the Council was keen to include everyone present to help to produce something really positive for Cornwall.

MH asked if the September round of meetings would be timely in order for the Partnership Boards to contribute to the process and how AS envisioned their participation. AS said that September was really good timing and she would

	<p>give a “Where we are now” update at that meeting, with details of the impact of conversations held with both individuals and groups, emerging themes and intentions for housing with support, the latter of which work was being carried out quite rapidly for due to demand. She would ask if what they had been hearing resonated with the Board and whether or not anything had been missed. MH asked that AS prepare some quite specific questions around themes in order to ensure that relevant information is gained. AS said that that was her intention.</p> <p>AS thanked everyone for the opportunity to attend the meeting to present the update and for the positive comments about neurodiversity. SWi said she was happy to share Plymouth’s post diagnosis research. AS undertook to follow it up with SWi.</p>	
<p>7.</p>	<p>Any other business</p>	
	<p>No other business declared, MH reminded attendees that they needn’t miss opportunities by waiting until meetings to relay information. They should send it to partnershipboards@healthwatchcornwall.co.uk and the team would ensure that it was disseminated in a timely manner.</p>	
<p>8.</p>	<p>Future meetings</p>	
	<ul style="list-style-type: none"> • Joint Learning Disability & Autism and Carers Service Users Event - 7 September - Zoom • Autism Partnership Board - 28 September - Teams • Joint Learning Disability & Autism and Carers Service Users Event - 23 November - Zoom • Autism Partnership Board - 14 December - Teams 	