

<b>MEETING NOTES:</b>	Meeting of the Autism Partnership Board
<b>DATE:</b>	Tuesday 5 October 2021
<b>LOCATION:</b>	Via Teams

## ATTENDANCE

Name	Position	Organisation
Mike Hooper (MH)	Partnership Boards Officer	Healthwatch Cornwall
Anne Oliver (AO)	Business Support Manager	Healthwatch Cornwall
Anne Bowdler (AB)	Primary Care Liaison Nurse for Adults with a Learning Disability	Cornwall Partnership NHS Foundation Trust
Ann Smith (AS)	Head of Commissioning for LD, Autism and Mental Health	Cornwall Council
Claire Martin (CM)	Deputy Director for Nursing	NHS Kernow
Christopher Burns (CB)	Self Advocate and Service User	N/A
David Burns (DB)	Self Advocate and Service User	N/A
David Allkins (DA)	Revenue and Benefits Admin Assistant and Self Advocate	Cornwall Council
Deborah Rees (DR)	Responsible for Transformation of Care	Cornwall Council
Dina Holder (DH)	Engagement Manager	Divas, Women's Centre
Sgt Flo Linscott (FL)	Diverse Communities Team rep	Devon and Cornwall Police
Heather Davidson (HD)	Parent Carer	Divas ICAM
Michelle Lobb (ML)	Director	Parent Carers Cornwall
Nory Menneer (NM)	Clinical Lead and Learning Disabilities Commissioner	NHS Kernow Clinical Commissioning Group
Rebecca Jelbert (RJ)	Clinical Psychologist, Adult Aspergers Assessment Team	Cornwall Partnership NHS Foundation Trust
Cllr Sally Weedon (SW)	Councillor	Cornwall Council
Steph Isaacs (SI)	Outreach Inclusion Worker	Cornwall People First
Vicki Allen (VA)	Adult Social Care Commissioning Manager with responsibility for Learning Disability and Autism	Cornwall Council

## APOLOGIES

Name	Position	Organisation
Anna Passmore	Patient Experience Lead	Cornwall Partnership NHS Foundation Trust
Caroline Finlayson	Speech and Language Therapist & Autism Lead	Cornwall Partnership NHS Foundation Trust
Darren Moyle	Behaviour Specialist	Spectrum

Emily Nicol	Mental Health Liaison Practitioner for the Learning Disability Teams (Green Light Nurse - promoting better mental health provision for people with LD and Autism)	Cornwall Partnership NHS Foundation Trust
Georgia Jenkin	Community Care Co-ordinator, Adult Care and Support	Cornwall Council
Helen Childs	System Director - Integrated Communities	Cornwall Partnership NHS Foundation Trust
Lerryn Udy	Advanced Nurse for Mental Health and Complex Cases	RCHT
Robin Gunson	Head of Developments	Spectrum
Sarah Caignet	Employment Support Officer	Cornwall Council
Sarah Thorneycroft	Housing Strategy & Partnerships Engagement Officer and Economic Growth & Development Directorate	Cornwall Council
Shelagh Mitchell	Healthy Cornwall Team Lead Health & Inequalities CHAMPs Team Manager	Cornwall Council
Suzanne Wixey	Service Director Adult Social Care and Support	Cornwall Council
Tazmin Hook	Self-Advocate	Independent Cornwall Autism Network
Zoe Cooper	Safeguarding Nurse Lead	RCHT

## ACTIONS

Action	Responsible	Status
Investigate changes to blue badge application process.	MH	Incomplete.
Update on Day Services.	MH / AS	Incomplete.
Convert Direct Payments information into easy read, for circulation.	AS / CG	Ongoing. CC to produce.
Share presentation to LDPB on the NHS Long Term Plan with APB members.	NM / MH	Complete. Circulated with minutes.
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.

Item	What was discussed	Action
1.	<b>Welcome, introductions and apologies</b>	
	<p>MH welcomed everyone to the meeting and reminded all it was being recorded for minuting purposes and of the meeting etiquette.</p> <p>Cllr Sally Weedon was introduced as the Cornwall Council's new elected Member representative on the Board. She explained she had experience of working with Autism and that she was pleased to be joining the Board.</p> <p>Everyone present introduced themselves.</p>	

	<p>MH reported that Nuala Kiely, Partnership Boards Officer, had moved on from Healthwatch Cornwall. The Board all wished her well for the future and expressed thanks her for her contributions over the last 3 years.</p>	
2.	<p><b>Minutes of the Meeting of the Autism Partnership Board held on 22<sup>nd</sup> June 2021.</b></p>	
	<p>The minutes of the meeting held on 22nd June 2021 were confirmed as a true record.</p> <p>Actions from the meeting:</p> <ul style="list-style-type: none"> <li>• NM had e-mailed his NHS Long Term Plan presentation to MH, who would circulate it with the minutes.</li> <li>• Conversion of Direct Payments information into easy read - Cornwall Council had agreed that this would be done. MH would circulate it to the Board upon receipt.</li> </ul>	<p>MH to circulate. MH to follow up and circulate.</p>
3.	<p><b>Update from members</b></p>	
	<p>MH and Jody Wilson from Healthwatch Cornwall had met with NM the previous day to discuss how the Partnership Boards would interact with the new LDA Programme Board. One of the roles of the Partnership Boards was to co-produce health and care policies and strategies in line with local priorities and the NHS long term plan. MH and NM would ensure that what came to the APB was aligned to the work programme of the LDAPB and, therefore, the NHS Long Term Plan, ensuring the opportunity to contribute effectively. NM said that the next discussion would be around formalising arrangements between the Boards.</p> <p>ML updated from Patient Carers Cornwall. She was pleased that PCC had been invited to participate in the LDAPB and had attended the previous week. PCC's training programme was being rolled out and the next training would be Circles of Support, for which there had been a lot of interest. It would be held via Teams.</p> <p>DH advised that the Divas had been meeting throughout the pandemic and were now getting back to delivering training. Their first live event, in collaboration with the Women's Centre, was a session with women offenders. Representatives from Devon, Cornwall and Dorset all met in Exeter. They had also presented remotely to the Cambridge Rape Crisis Centre. Those sessions had been set up and run by peer advocates. Over the next 6 months they would be investigating new funding streams and links within sexual abuse and domestic violence, with special focus on Autism and learning disabilities.</p> <p>SI said that Cornwall People First were restarting forums in November, invites had been sent to day centres, and a Saturday group was up and running. She invited members to let her know of any further days centres that would like to be involved.</p> <p>RJ updated from the Diagnostic Team, acknowledging the long waits for people seeking a diagnosis of Autism. The team were working hard to reduce the backlog and to work with the Trust and commissioners to look at how the service could expand to be better resourced moving forward, both in terms of</p>	

	<p>providing diagnoses and also post-diagnostic support.</p> <p>RJ continued, sponsored by Cornwall Partnership NHS Foundation Trust, with a research grant from the Small Business Research Initiative, there was a multi-site (5 sites across the country) national research project for an app called Brain in Hand to help people with Autism in everyday functioning.</p> <p>FL had met with Cornwall People First the previous week and now planned to attend some of their forums to raise awareness of hate crime. The following week was Hate Crime Awareness Week and his team would be very busy touring Cornwall and visiting those key contacts and organisations that helped the Police to support victims. MH asked FL to send him any information which could be circulated to Partnership Board members.</p> <p>CB said the Brain in Hand app was great, providing it worked on all phones. There was a lot of poverty in Cornwall and not everyone could afford expensive smart phones, hence national campaigns to combat digital exclusion. RJ said that she would feed CB's comments back to the national research team leading the work. <i>Note: Immediately following the meeting, RJ updated: The research team have responded as follows: Unfortunately at this stage, the research grant does not allow for funding to cover the costs of smart devices. However if the study proves a success, it is hoped that such devices might be more readily available so that all people who wish to use this autism support App are able to. The research first needs to prove such technology is actually considered helpful and effective.'</i></p> <p>CB had attended autism training at Torpoint, supplied by a private provider. It had been OK but the self advocate involved in preparing the training had no involvement on the day. Attendees were mainly parents from Plymouth.</p> <p>DR said that she believed that improvements had been made in ensuring that people with autism and a mental health diagnosis could be supported in wards within Cornwall.</p> <p>The Divas would be discussing hate crime, how it affected those with learning disabilities and Autism and violence against women with Chaos TV that afternoon. The recording would go out during Hate Crime Awareness Week.</p>	
<p>4.</p>	<p><b>Feedback from the Learning Disability and Autism Service Users and Carers Event on 7 September 2021</b></p>	
	<p>MH fed back from the recent Learning Disability, Autism and Carers Service Users Event.</p> <p>The main topics of conversation were:</p> <ul style="list-style-type: none"> <li>• <b>Hospital passports</b> - Jane Rees had provided the latest version of the hospital passport for people with learning disabilities for the group to comment upon. Some very good practical feedback was received which Jane would be taking back to share with other acute hospitals.</li> <li>• <b>Direct Payments</b> - the new Cornwall Council lead officer for Direct Payments would be discussing how they could be used with the Autism PB. <i>Note: That agenda item was deferred. VA said that the Council would look to produce information in easy read.</i></li> </ul>	

- **Access to NHS services, particularly GP's** - accessing GP services had been raised at previous meetings throughout Covid, and whilst it needed to be stressed that this was not indicative of all GP practices, self-advocates reported that they felt that access had worsened in recent months.

MH played a very impassioned recording from the Service Users event in which people with learning disabilities and/or Autism highlighted the difficulties people with communicative issues were experiencing in trying to get support from their GP.

HD added that she had also said at the meeting that GPs are gatekeepers but did not have the right training. She remembered a discussion about 5 years ago about how that could be addressed but nothing had been done.

MH said that Healthwatch Cornwall attend locality meetings and all the comments will be fed back into these, nothing will be lost. AB urged all to use the PALS service to continue to feedback experiences and views. There was also the opportunity to join Patient Participation Groups (PPGs) at local GP surgeries. The issue was also being raised as an accessible information standards matter at System level and at multi-agency meetings.

One reason for needing access to GPs was to discuss and review medication. It was noted that over the last ten years, the use of anti-psychotic drugs had been reduced but anti-depressants and epilepsy drugs were on the increase.

ML said that, as a parent, the recording was raw to listen to. It was a postcode lottery as to the service an individual would receive. Her lived experience was OK as her local surgery had a LD GP specialist based there. She agreed that training needed to be put in place. MH said that feedback received by HC generally demonstrated wide differences in GP access across the County.

AB said that Oliver McGowan training in LD and Autism was being rolled out but she was unsure of timescales. It was acknowledged that a frequent comment was, "I can't get past the receptionist". AB said that awareness training was offered to GP practices but acknowledged this it was not specific to Autism.

NM advised that GPs already had training sessions related to LD health checks. The communication element of that was relevant to all people, not just those with learning disabilities and RJ shared a link to an autism tool kit page on the Royal College of General Practitioners <https://www.rcgp.org.uk/clinical-and-research/resources/toolkits/asd-toolkit.aspx>.

CB said he was glad that the recording had been shared. He had to ring his surgery himself and this reiterated how hard it was to communicate with them.

There was a national shortage of GPs and especially in the south-west, which was not helping.

DH said it had been really impactful to hear service users speaking from the heart, rather than it being fed back by professionals. She would like to get relevant permissions to share a tool she has, to get a good consistent programme together.

MH agreed and reiterated that's why the group was set up, such discussions wouldn't happen at a formal meeting.

It was noted that the Divas had collaborated with Lancaster University on a

	<p>Clare’s Law information campaign, which would be going live on 20<sup>th</sup> October. It would be an online event, with the Divas in attendance, along with Sarah Treeby from the Police.</p>	
<p><b>5.</b></p>	<p><b>Presentation - Delivering Better Care</b></p>	
	<p>VA gave a PowerPoint presentation on Cornwall Council’s new strategy for Adult Social Care and asked for feedback on the 6 core themes.</p> <p>She gave a brief overview of Adult Social Care and what they do, acknowledging that resources meant that they had to re-think how best to ensure independent living. They wanted to involve those with lived experience as well as providers. A survey had been widely circulated and they had identified 6 areas for change.</p> <p><b>Own front door, with commissioned care</b></p> <p>ML said that at a recent meeting with Ocean Housing, it was noted that when a child moves into adulthood and lives at home, Cornwall Council had already spent a lot of money adapting their current surroundings (in this case social housing) as a family home. Why couldn’t the approach change to rehousing the parents, therefore enabling the young person to stay long term in the home and the community they knew.</p> <p>VA said that the Council now had a Head of Service joint post between Adult Social Care and Housing which should enable a more strategic approach to housing support for people with Adult Social Care needs. There was a workshop in November with local providers of social housing, with the intention to work co-productively moving forward. There was a need for more affordable homes in general but it was important to be aware that the infrastructure was also key for Autism - it needed to include pathways and parks as well as shops, cafes, etc.</p> <p>HD asked about opportunities for Autism villages - some would love their own community. VA said the national strategy was for integration and valuing inclusion but she took the point on and said it would be kept on the table. AS was connected with the National Autistic Society and would liaise with them.</p> <p><b>What people want from their daily structure</b></p> <p>ML said it depended on the support available to individuals to access employment. SW said that improved transport in Cornwall was key to accessibility. DB said investment would be needed in technology to help people work from home. HD said it was about recognising the adjustments needed and providing support, and what about apprenticeships for those who can’t reach Level 2 in education?</p> <p>The Divas had been keen to start low level OCN training with a view to then helping people to move up. However, obtaining funding for the work they wanted to do and for their target group had proven very difficult. It would be worth looking creatively into training, employment and volunteering as a route in to that in order to overcome barriers faced by providers that were not Autism specific. That could, though, be a positive if it encouraged collaborative work across the sectors. CM suggested Cornwall be innovative suggested we engage with the 10 biggest employers in Cornwall to collaborate</p>	

on a scheme for a new type of apprenticeship - a “Cornish Apprenticeship” to help raise esteem. DA suggested an online website for people in Cornwall seeking employment as a good start

Delivering Better Care targeted working groups would be set up to develop the themes. MH said Sheila from the CHAMPs had expressed a willingness to participate in such groups. DH and the Divas would also be interested.

NM said that NHS England had given £20K to help train mainstream mental health services around working people with Autism. Having heard this conversation about training, he would be interested to talk to members who had ideas about how it could be quickly delivered.

### **Preparing for Adulthood**

This important phase now had its own Board. NM said it was about the ability to give life choices that were not directed by agencies. HD mentioned the need to ensure support and help around benefit entitlements. SW asked if volunteer mentors could help with this.

### **Staying Healthy and Well**

HD said that we already have LD wellbeing checks and she asked what progress had been made around Autism wellbeing checks. It was an objective in the NHS Long Term Plan but it was not specific about annual checks. NM said that annual health checks were proposed three years ago. There was a trial being undertaken currently and results were awaited. ML said it needs to be linked into benefits and support, it was hard to navigate and not fall through the safety net.

Staying healthy and well was not just about physical health, it included sexual health and accessible information about services such as social prescribers. A directory would be good, but it would rely on providers to keep it up to date. The Council would be looking at locality offers.

DH responded that she thought that Tigger Pritchard from NAS and Tazmin Hook and HD from ICAN should be involved in that. She could assist - developing the training and supporting the group - and she currently managed a peer mentor project for women at risk of offending and /or who have offended, so if mentoring was considered she had relevant experience. SW suggested subjects such as promoting healthy lifestyles, exercise and nature - being outside as a therapeutic asset, as well as connectivity within the community.

DB made the point that some services, such as cancer services, provided access to liaison services if requested by a GP. If there was a similar liaison service for those on the Learning Disability register that would improve access to extra support such as Mental Health Services.

CB said a lot of people had to make such financial choices as being able to eat or to access healthy lifestyles. With regard to employment, there had been massive investments nationally in transport focusing North to South, but Cornwall still had rolling stock from 20 years ago. The Space Port in Cornwall, for example, could offer high skilled jobs.

RJ had heard feedback from some staff in mainstream services that, due to lack of capacity, resource and training, they were struggling to offer

	<p>appropriately adapted support to individuals with Autism that had significant mental health difficulties. There was also a need for more specialist Autism specific interventions for those who might need support around core features of Autism but who might not be eligible for mainstream mental health services.</p> <p>SI said it was about increased choice and control. We needed to focus on what people could do and not what they couldn't.</p> <p>DB said support needed to be flexible about what and when, eg, when a carer came in. HD said that Personal Assistant "banks" were needed, as well as more training. It would be good if service users could access information on careers themselves, to address barriers.</p> <p><b>Staying Safe</b></p> <p>CB said more understanding from communities was needed in order to be more inclusive. DH said those with Autism were less likely to report and get the help they needed and that women and girls were especially vulnerable - there needed to be a specific focus around that, especially with regards to domestic violence, sexual abuse and harassment.</p> <p>HD said it was about understanding relationships. Those with Autism tended to see things in black and white and take people at face value - they didn't see manipulation. She would like to see healthy relationship education at school level.</p> <p>FL said that Police control room staff had input into learning disability and communication issues and his team would carry on helping them to understand, especially issues specific to Autism. They were really keen to ensure that everyone could engage effectively.</p> <p>MH said it would be useful for the Service User group to have a discussion on the whole document at its next meeting.</p>	
<p><b>7.</b></p>	<p><b>Any other business</b></p>	
	<p>ML wanted to highlight the change in the blue badge application process, which was now being centralised through the Department for Transport who then sent applications on to Cornwall Council. That meant having to re-submit all evidence again, even for renewals, and it was especially difficult finding and collating all this evidence after transition.</p> <p>DA raised the issue of PIP and how mobility was scored and taken into account for Blue Badge applications - psychological stress and the ability to plan and follow a journey. He felt there were GDPR issues over the short application.</p> <p>CB said he was at a meeting the previous week where people from diverse backgrounds had talked about their journeys, for example, one person shared that 10 years ago there had been no opportunities to attend universities, people were stuck in day centres. MH would follow up directly with CB outside of the meeting.</p> <p>FL encouraged all to share the information about reporting hate crime.</p> <p>ML asked when would day services re-start in a meaningful way? Residential</p>	<p>MH to investigate.</p> <p>MH to follow up with AS</p>



	<p>services are not able to access day services.</p> <p>MH reminded attendees that they needn't miss opportunities by waiting until meetings to ask questions or relay information to the Board. They should send it to <a href="mailto:partnershipboards@healthwatchcornwall.co.uk">partnershipboards@healthwatchcornwall.co.uk</a> and the team would ensure that it was addressed and/or disseminated in a timely manner.</p>	
<p><b>8.</b></p>	<p><b>Future meetings</b></p>	
	<p>The Board unanimously agreed to continue meeting online, with members stating that it was time efficient and eliminated travel logistics.</p> <ul style="list-style-type: none"> <li>• Joint Learning Disability &amp; Autism and Carers Service Users Event - 10am, 23 November - Zoom</li> <li>• Autism Partnership Board - 10am, 14 December - Teams</li> </ul>	