

MEETING NOTES:	Autism Partnership Board
DATE:	17 th September 2019
LOCATION:	Top Floor meeting room, Truro Library, Union Place TR1 1EP

ATTENDANCE

Name	Position	Organisation
Nuala Kiely (NK)	Lead Partnership Boards Officer	Healthwatch Cornwall
Mike Hooper (MH)	Partnership Boards Officer and Minute Taker	Healthwatch Cornwall
Ben Seemarks (BS)	Commissioning Officer	Cornwall Council
David Allkins (DA)	Revenue and Benefits Admin Assistant and Self Advocate	Cornwall Council
Dina Holder (DH)	Community Engagement Manager	The Women's Centre
Elizabeth Campling (EC)	CHAMPS supporter	Cornwall Council
Katherine McQuay	Social Worker, Kerrier North	Cornwall Council
Katie Wheeler (KW)	CHAMPS	Cornwall Council
Nicola Hancocks (SAT NEXT TO RJ)	Trainee Psychologist	Outlook South West
Nory Menneer (NM)	Clinical Lead and Program Manager for Learning Disabilities	KCCG
Rachel Brown (RB)	Clinical Psychologist and Manager	Spectrum
Rebecca Gay (ReG)	Access Team	Cornwall Council
Rebecca Jelbert (RJ)	Clinical Psychologist Adult Aspergers Service	Outlook South West
Richard Gittens (RG)	CHAMPS	Cornwall Council
Sarah Stevens (SaS)	Partnership Coordinator	Pluss
Stephanie Shard (SS)	DIVA	The Women's Centre

APOLOGIES

Name	Organisation
Abigail McCormack	Outlook South West
Cilla Holt	Cornwall Council
Colin Blandford	Cornwall Council
Ellen Hearn	CPFT
Gill Pipkin	Citizens Advice Bureau
Helen Childs	KCCG
Councillor Jackie Gammon	Cornwall Council
Kelvin Yates	Cornwall Council
Kerry Crawley	Cornwall Council
Melanie Wiesel	Cornwall Council
Sarah Thorneycroft	Cornwall Council
Suzanne Wixey	Cornwall Council
John Groom	KCCG
Tim Francis	KCCG

ACTION LOG

DATE	ACTION	RESPONSIBLE	STATUS
17/09/2019	Commissioning Team to provide an update on the Day Services consultation to the next meeting of the Board.	BS	Outstanding
17/09/2019	Invitation to Dr Shankar to attend the next meeting of the Board.	NK	Outstanding
17/09/2019	Raise the ongoing difficulties with diagnosis and assessment with Paul Cook.	NM	Outstanding
17/09/2019	Help to publicise CHAMPS events.	NK	Outstanding
17/09/2019	Invite KY to attend the next meeting of the Board to discuss the Adult Autism Strategy.	NK	Outstanding
17/09/2019	Meet with Councillor Jacquie Gammon to raise concerns for people with mental health issues.	NK	Outstanding
20/06/2019	All - Please send any views about how the non-emergency police number should be set up to improve accessibility for people with autism to Julie Jamaa Ben M'Hand. Contact details circulated by email.	All	8/07/19 JJBM email address circulated 17/09/19 Feedback ALL JJBM left Await re-placement
20/06/2019	JJBM - Present at the next Board meeting about Devon & Cornwall Police's consultation on improving accessibility of 101 number for people with autism	JJBM	17/09/19 JJBM left Await re-placement
20/06/2019	KY to meet with CC/KCCG commissioners as part of integrated adults and children's autism strategy.	KY	Await response from KY
20/06/2019	KY to liaise with Amy Claridge to find out more about the minibus' fuel allowance	KY	Ongoing
20/06/2019	Email to thank Katherine Neilson and Pentreath for "Living to Work Well" project	NK	Completed
20/06/2019	Further discussion about differences between, Health and Social Care personal budgets	HD/NK	16/09/19 Information sent to HD.
20/06/2019	KY to liaise with AC and confirm venues and dates for drop-in engagement sessions regarding day services. NK to circulate when confirmed.	KY/AC/NK	Completed NK shared info on 18/07/19 and 8/08/19

20/06/2019	KY to liaise with AC and confirm contact details, website and phonenumber for day services engagement project. NK to circulate when confirmed.	KY/AC/NK	Completed NK shared info on 18/07/19 and 8/08/19
20/06/2019	Consider where further discussion about standards of care provided by PA's should be addressed.	SM/NK	Ongoing No decision made
19/03/2019	Shelagh Mitchell to speak to Elizabeth Campling to get a review of scripts available for Council staff to use when speaking to someone with autism.	SM	Ongoing Rebecca Gay attending Sept meeting.
19/03/2019	Board to create a pathway through services for someone with autism. NK will ask Rebecca Jelbert from Outlook South West, Dr Rohit Shankar at CFT, Liz Cahill at NHS Kernow to help	NK/NM	Ongoing. To be discussed at Sept meeting
19/03/2019	Hugh Evans to find out from Gill Gilbert at the Council what happens to minibuses at the end of their lease for day services and why they aren't being replaced	HE	Outstanding
19/03/2019	NK/KY to liaise with Board members about possibility of event with professionals and service users to look at autism strategy and create workable action points for push forwards	NK/KY	Ongoing. No decision about date made.

Item	What was discussed?	Action
1	<p><u>Outstanding items from the last meeting</u></p> <p>NK provided updates on matters outstanding from previous meetings. These are detailed in the Action Log, above.</p>	
2	<p><u>Updates</u></p> <p>NK invited those present to provide updates and feedback on their work since the last meeting of the Board. Responses to questions posed by Board members were also provided.</p> <p>Spectrum</p> <p>RB stated the following:</p> <ul style="list-style-type: none"> • The Pearl Centre, which had not been commissioned but was funded by Spectrum, had closed at the end of July, having been open for 16 years. • Monthly open sessions were now being held. To receive details of them, people could email william.fox1@spectrumasd.org to be added to the mailing list. <p>Divas</p> <p>DH stated the following:</p> <ul style="list-style-type: none"> • Some of the Divas were learning to become peer educators. • 70 members of the Police force and other professional staff had been trained to understand why women with a learning disability and/or autism could find it difficult to report incidences of domestic and/or sexual violence to the Police. The Board would be informed of any future developments. • Recruitment was underway for Divas 2. The new recruits would be trained by the original Divas and there would be a focus upon consent and healthy relationships. • Rod Landman, Association for Real Change (ARC), South West Regional Officer, had been working with the Divas having successfully bid for Comic Relief funding to develop an awareness raising session. • SaS said that the intention of the sessions was to teach women with LD and autism what good relationships and partners looked like and the differences between healthy and bad relationships. Divas 2 should also help people to be able to identify warning signs and what they meant, providing individuals with greater confidence and competence. <p>Leaflets detailing the work of the Divas project were made available to attendees.</p> <p>Cornwall Council Day Services Engagement</p> <p>BS provided the following update:</p> <ul style="list-style-type: none"> • Around 1400 surveys had been sent out in an attempt to get as wide a response as possible. So far, nearly 475 completed 	

<p>surveys had been received and it was hoped that a 50% return rate could be achieved by the closing date the following week.</p> <ul style="list-style-type: none"> • From those completed surveys, it appeared that actionable feedback was being received. Individuals were clearly stating what they felt was required to meet their needs. • Socialisation and combatting isolation through the creation of safe environments in which to be challenged by peers without the risk of ridicule was coming through as a key factor. • They were halfway through a second round of drop-ins and workshops. • Tenders had been invited for a voluntary organisation to lead on the co-production phase. The new contracts, which would start in 2021, would enable more choice for service users. • NK said that Healthwatch Cornwall was optimistic that the Council had learnt from mistakes made with previous consultations. • There was a direct dial number and a direct email address for people that required assistance to complete the survey. However, the workshops seemed to be working and attendees were saying that one to one help was not necessarily required for completing the survey. <p>Healthwatch Cornwall</p> <p>NK provided the following update:</p> <ul style="list-style-type: none"> • NHS England had asked Healthwatch Cornwall to find out what people thought about Special Care Dental Services. The focus of the work was how the service worked for adults with a learning disability and/or autism who could not safely access high street dental surgeries due to, for example, the need for sedation, high levels of anxiety or other complex health needs. As people using the service may not be able to verbally express their views about the care they receive, a focus group for both users and carers would be held on 24th September 2019 from 2pm to 3.30pm in Truro Library meeting room. Refreshments and reasonable expenses would be provided. There would also be an opportunity to meet representatives from NHS England. People were asked to let NK know if they planned to attend. The survey could be accessed here and could be returned by freepost or email. • One role of Healthwatch Cornwall was to identify themes to approach providers and carers with. NK had recently received five different emails regarding autism services and specifically assessment and diagnosis which were being flagged up to NHS England and Healthwatch England. • A new group was being formed as an add-on to the Learning Disability Partnership Board. The key aim was to provide opportunities for peer support and the target audience was people that would not want to attend a formal meeting. Any adult with a learning disability was welcome to attend but people were asked to notify NK in advance as refreshments and lunch would be provided. The first group would start at 	<p>Commissioning Team to provide an update on the Day Services consultation to the next meeting of the Board.</p>
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10.30am on Thursday, 24th October 2019 at Truro Community Library.

Kernow Clinical Commissioning Group

NM and RJ provided the following update:

- The KCCG had identified similar themes to those referred to by NK, particularly the lack of timely diagnosis and the lack of post-diagnosis help. NM was requesting funds and asking for autism to be prioritised but available money was finite. DA suggested that a cheap way to start could be to produce an online resource or a leaflet that detailed advice for family/friends post diagnosis. RJ said that Outlook South West had created an online directory and online groups for peers. RB said that Spectrum held open sessions and sent out autism specific information. Information was also available on the Cornwall Council website.
- The original diagnostic resource had been £200,000 but since then need had quadrupled. A bid for additional mental health funding had failed as the KCCG had other priorities.
- For future commissioned services, NM was keen to clearly separate the need of learning disabilities and autism.
- In response to a question from NK regarding the various assessment and diagnostic services currently available, NM said that the childrens diagnostic services, which were split between the age groups of 0-5 and 6-16, were overwhelmed. Outlook South West offered a service for adults that had not had a mental health diagnosis. Those with a mental health diagnosis were assessed by the Cornwall Foundation Trust (CFT). It was not currently known how many people were assessed by the CFT.
- Outlook South West's referral rate had recently changed to clinician only following the decision to suspend the self-referral option. This approach would help to provide triage information, which had been lacking historically. Referrals could come from any professional that could evidence need ie. a GP, a social care worker, a therapist etc. A referral form was available on the KCCG website.
- In response to a concern raised by NK that some GPs were advising that diagnoses were not required as they took too long, RJ said that, on the contrary, some GPs were over-referring early on. NM added that it was sometimes necessary to commission in to fill the gaps. However, there was another option for patients. Under Patient Choice (PC), everyone had the right to be referred to NHS services anywhere else in the country, including referral to The Lorna Wing Centre. If every GP promoted that then the KCCG would have to reconsider its position. RJ said that the KCCG did advise that patients discussed PC with their GP, particularly those with NHS issues that could not be addressed within Cornwall.
- Referrals were currently being seen within 17 months, an improvement on the previous two year wait. NK asked who was the best person from the CFT to invite to discuss referral times with the Board. RM suggested Dr Shankar.

NK to invite Dr Shankar to the next meeting of the Board.

	<p>She had then devised an email, paper copies of which were circulated to the Board. Once the content had been considered and agreed it would be converted into easy read.</p> <p>The Board made the following suggestions:</p> <ul style="list-style-type: none"> • The referral information could have an option to state who is filling in the form, the service user or a carer on behalf of the service user. A tick box option would suffice. • Upon initial contact there could be questions to find out if the person had additional needs or could struggle with aspects of the process. • EC would email to ReG a script previously used which opened with the question, ‘Do you have autism?’. • There was a guide regarding Personal Independence Payment (PIP) available on the National Autistic Society website. Often there was a focus upon the ability of an individual to complete everyday tasks, such as making a cup of tea, which neglected the fact that there could be struggles with earlier elements of the process. <p>NK asked that ReG keep the Board updated.</p> <p>ReG invited Board members to contact her with any comments or suggestions at rebecca.gay@cornwall.gov.uk.</p>	
4	<p><u>The Adult Autism Strategy</u></p> <p>NK said that Kelvin Yates, Cornwall Council (CC), had been due to attend to discuss the Adult Autism Strategy. In his absence she stated the following:</p> <ul style="list-style-type: none"> • The Strategy had been agreed in December 2017. NK had been in post at Healthwatch Cornwall since February 2018. In the time since then there had been no progress with regard to the implementation of the Strategy and it had been downgraded to a working paper. • She was not confident that a revised Strategy would have been agreed and signed off by the Board’s next meeting. • Currently, there was work to align services offered to children with those for adults. • Assessment and diagnosis were key. There needed to be a definitive pathway to fit into or align with the Strategy, incorporating local issues. • There were concerns for people with mental health issues. • She was due to meet with Cornwall Councillor Jacquie Gammon, who she would raise the Board’s concerns with. • The Strategy would remain a standing item on the Board’s agenda. <p>NM expressed the view that the pathways were clear but processes were slow. The issues were due to KCCG and CC funding and it should be acknowledged that achieving small successes was preferable to doing nothing at all.</p>	<p>NK to invite KY to attend the next meeting of the Board.</p> <p>NK to meet Cllr JG to raise concerns for people with mental health issues.</p>

5	<p><u>Social Prescribing</u></p> <p>Sarah Stevens from Pluss gave a presentation on social prescribing, a copy of which is attached as an Appendix. She stated the following:</p> <ul style="list-style-type: none"> • Social prescribing in Cornwall was provided by Pluss and Volunteer Cornwall, it was possible to find extra support for post-diagnosis services. • Work was being undertaken with, for example, GPs to identify gaps and potential funding for projects and with Outlook South West. RJ commented that it did not include the Aspergers Service. SS continued, stating that there was a willingness to support and work with as many service providers and agencies as possible to help to improve support for people. • Referrals were seen four times in a six month period. There were no home visits but there was a befriender scheme that enabled connections and introductions to be made. • For quality assurance purposes and to help to provide comfort for individuals attending alone, staff visited the groups that the referred people to. • Warwick-Edinburgh and GAD mental wellbeing screening tests were carried out both at the referral stage and at the end of contact. • The Health and Wellbeing plan could often enable matters to be viewed from a different perspective, both positively and negatively. <p>In response to issues raised by attendees, SaS stated the following:</p> <ul style="list-style-type: none"> • Some women needed greater support than others in order to feel comfortable in such scenarios but there were no hard and fast rules and the approach was not subject to Key Performance Indicators. Also, the fact that home visits were not part of the practice had not been flagged as an issue. • Information was being collected to hopefully show that social prescribing helped to reduce the number of people visiting the GPs with non-medical issues. Help and information for individuals was out there but it was often difficult for people to identify it. There was a need for a community based model to help in this area. • The Positive People projects were available to help individuals who were out of work but Social Prescribers were available to all (venues detailed in the Appendix). There were also other providers of social prescribers. • The first six months had just been completed and feedback was currently being collected. • Two of the current Social Prescribers were ex-nurses but there was not a requirement for that medical background. They had received training on many areas, including first aid and suicide awareness and would receive more. Learning Disabilities and Autism would be added to the training list. • It could be seen as counter-productive for people to see their GP before seeing a Social Prescriber. GPs that understood 	
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	<p>the role of a Social Prescriber and wanted to identify gaps had been very supportive. The key role was to link people in with the most appropriate support for them.</p> <ul style="list-style-type: none"> • It hadn't been the case that people would see posters and contact the organisation direct but it that was an area that needed to be pursued as GPs had originally indicated that referral rates would be much greater than they had proven to be so far. <p>To find out more, SaS could be contacted on 07341004929 or at sarah.steven@pluss.org.uk.</p>	
6	<p><u>Direct Payments Review</u></p> <p>Derek Hoddinott, Direct Payment Reviewer, Cornwall Council had been due to present the item but was not in attendance.</p> <p>In the absence of DH, NK provided background to the work being carried out by Cornwall Council in relation to its approach to Direct Payments.</p> <p>As it had become apparent that the old policy was not clear, a new policy had been drafted which had been launched for consultation the previous week. The new version was both a policy document and a guide to Direct Payments which contained links to supporting information.</p> <p>The survey on the draft Policy was targeted towards current and future DP recipients, carers, advocates and healthcare workers. Board members were urged to get the message out to ensure that the survey reached as many people as possible.</p> <p>A series of workshops had been set as follows:</p> <ul style="list-style-type: none"> • 1pm, Monday, 7 October 2019 at Echo Centre, Barras Place, Liskeard PL14 6AY • 1pm, Wednesday, 9 October 2019 at Trethorne Leisure Park, Kennards House, Launceston PL15 8QE • 1pm, Thursday, 10 October 2019 at Redruth Community Centre, 9a Chapel Street, Redruth TR15 1AW • 1pm, Tuesday, 15 October 2019 at Lescudjack Centre, Penmere Close, Penzance TR18 3PE • 1pm, Wednesday, 16 October 2019 at Merlin MS Centre, Bradbury House, Hewas Water, St Austell PL26 7JF • 1pm, Thursday, 17 October 2019 at The Dracaena Centre, Dracaena Avenue, Falmouth TR11 2ER <p>In addition, three drop-in sessions had been set as follows:</p> <ul style="list-style-type: none"> • 9.30-13.00, Wednesday, 2 October 2019 at Pool Innovation Centre, Trevenson Road, Pool, Redruth TR15 3PL • 9.30-13.00, Wednesday, 9 October 2019 at Liskeard Town Council, Public Hall complex, 3-5 West Street, Liskeard PL14 6BW • 9.30-13.00, Friday, 11 October 2019 at St Austell Conference Centre, St Austell Business Park PL25 4FD 	

	<p>The CHAMPS had helped to create an easy read contract document. However, the policy document was not available in easy read, making it very difficult for people to have the necessary information available to them to complete the survey. NK had highlighted the issue to DH and it was hoped that the deadline would be extended accordingly once such a document had been produced.</p> <p>DH raised concern regarding the number of different Council surveys and consultations that were open at any one time. Better coordination was required, as was support for voluntary groups. NK said that she had raised the matter with the Council but the problem was systemic. An overarching schedule had been requested but such a document was not available due to unknown contractual timescales.</p>	
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NEXT MEETING	10.30am - 12.30pm
DATE	Tuesday 17 th December 2019
LOCATION	Truro Community Library, Union Place, Truro TR1 1EP