

MEETING NOTES:	Autism Partnership Board
DATE:	18th September
LOCATION:	Wesley Halls, Redruth

ATTENDANCE

Name	Organisation
Nuala Kiely	Healthwatch Cornwall Acting Chair
Sophie Smith	Healthwatch Cornwall Minute taker
Andrew Gray	Cornwall People First (in attendance)
Alison Stephens	Outlook SW
Nicola Hancocks	Outlook SW
Rebecca Jelbert	Outlook SW
Katie Wheeler	CHAMPs
Elizabeth Campling	CHAMPs/Healthy Cornwall
Richard Coventry	Cornwall People First
Chris Jordan	Cornwall People First (in attendance)
Sam Edwards	NHS Kernow Interim programme manager TCP
David	CHAMPs
John Groom	NHS Kernow Director for integrated health and care

Steve Ford	Volunteer Cornwall Viva project
Emma Corlett	NHS Kernow children's' commissioning
Suzanne Wixey	CC Service director adult care and support
Ginette Trewren	CC employability team
Rachel Brown	Spectrum /The Pearl Centre
Tazmin Hook	Self-advocate
Heather Davison	Carer/PCC/self-advocate
Colin Blandford	CC co-production/engagement officer
Stuart Cohen	CC commissioning manager
Jane Rees	Manager LD and Autism manager RCHT

APOLOGIES

Name	
Paula Volkner	Rose Taylor
Rob Rotchell	Zoe Cooper
Fiona Whitehead	
Graham Wilkin	
Tim Francis	
Richard Sharpe	
Helen Childs	
Mel Wiesel	
Michell Lobb	

Item	What was discussed?	Action
1	<p>Update on Partnership Board development NK</p> <ul style="list-style-type: none"> • More service users and carers will be recruited New Co-Chairs. 1 self-advocate and 1 elected member of CC. • Cllr Jackie Gammon will join us in December. • A role description for the self-advocate post will be put together and circulated • PB working group overseeing all 4 PBs meet next week. Updates will be given 	<p>NK to circulate</p> <p>NK to give updates</p>

	<ul style="list-style-type: none"> Information gathering via survey and ER hardcopy to look at what involvement current members want in future. https://www.surveymonkey.co.uk/r/PB_involvement 	
2.1	<p>Action plan from the 2010 National Autism Strategy NK .Puts legal obligations on local councils and NHS. (SC reminded the Board that Cornwall Council Autism Strategy remains a working document.)</p> <ul style="list-style-type: none"> MUST have an autism lead None identified as adult Lead in Cornwall. SC was fulfilling some of the role but will shortly move post MUST develop a plan for how they will commission local services for adults and commission services considering local needs PB not sure this is happening MUST provide autism awareness training for all staff MUST provide specialist autism training for key staff including GPs and community care assessors RB there will be training for CC community care assessors. HD. Funding for wider training delivered by 14 self-advocates had finished. Support from the Board that future funding should be considered SC No training currently commissioned. HD There is e-training for professional delivered by NAS plus a 3 hour workshop. (NB. Training links in to points on Action Plan appendix 1) MUST appoint a lead professional for diagnostic and assessment services and ensure there is a clear pathway EC/RB/AS Pathway is not at all clear. There is a Children’s commissioning Lead (Kay Hill) and ops Lead (Sue Newman). MUST improve the transition process and should have transition procedures in place for those using mental health services. EC Transition in place now up to 25. RJ/AS/RB Young adults in transition fall between Outlook SW and CPFT and don’t get MH mainstream 	<p>SC,NK to ask within CC who will fit this role</p> <p>SC/SE to find out more</p> <p>JG/SE/Outlook SW (?? Who rep from Outlook SW will be) Meeting TBC between NHS Kernow, CPFT and Outlook SW outside of this meeting.</p> <p>NK rep from CPFT to attend the next meeting</p>

	<p>services. EC the MH condition has to be diagnosable and not sub- threshold e.g. low level anxiety. T RJ/AS/RB/ EC Disagreement between CFT And Outlook SW around who carries out assessments for who, especially adults with MH.</p>	
2.2	<p>Cornwall Council Autism Working Paper Action plan. Each action with a short term goal was reviewed. Without an Autism Lead it is not apparent who will ensure the actions “will be actioned”. The short term goals should be within 6 months (October deadline) but we are unlikely to meet the target. Appendix 1 is the Action plan with discussion notes beside each action.</p> <p>PB congratulated TH and HD on the work they have done in creating and maintaining a FB page to engage and support adults with ASC.</p> <ul style="list-style-type: none"> • General • Over 40’s • Females <p>SW An excellent example of technology being used by service users. The PB offered support to future plans around social media interventions.</p> <p>Following on from the support in Cornwall website update, PB asked to review to see if fit for purpose.</p> <p>Development of further scripts for those with ASC to use whilst contacting CC. Exact scripts not decided. CHAMPS and accessible communications team both aware of need for this</p>	<p>TH to send out FB link to All</p> <p>All to check out www.supportincornwall</p> <p>EC to email Debi Lewis</p>
3	<p>What happens next with Action Plan See: Action plan update (Appendix 1)</p> <p>Further discussions regards Leads for Autism within children’s’ and adults and who has overall responsibility for which part of the diagnostic and assessment service. SE Diagnostic service is Outlook SW. RJ Outlook SW is one part of the diagnostic pathway, others not so clear. EC Sue Newman ASDAT lead works with Jo Lewis (RCHT).Liz Cahill commissioning. All children soon to go through single diagnostic pathway. Part of the One Vision plan. Rest of PB not aware that this is happening and would like a full update.</p> <p>EC Most people with autism diagnosed in childhood.</p>	<p>EC/AK/RJ to provide organisational chart</p>

	<p>There is a push away from diagnosing children with ASC as it over medicalises their condition. They will be put on the SEND register. It could prevent them getting jobs when labelled. GT this is unlawful under the DDA. AK ASC is not a medical condition, it's a neurological difference.</p> <p>EC Bottom level (4) of statements don't qualify for EHP (???)</p> <p>55% of schools do buy in to support RB/TH/HD/AS when did this pathway begin? EC did not clarify.</p> <p>HD/TH. Diagnosing children early provides much needed help, preventing mental health problems (which can be masked) in adulthood. Children doing well academically are missed. Not acceptable.</p> <p>AS/RJ Telling parents that an ASC diagnosis causes stigma, it is a dangerous thing. Pressure will also be put on Education services.</p> <p>RB concerned that Cornwall is not using national guidelines to diagnose LD.</p>	<p>EC to provide documents/policies explaining which children do/don't get diagnosed.</p>
4	<p>Pain and Training presentation by Tazmin Hook.</p> <p>Due to timing this presentation was not given enough time.</p> <p>Pain scales used for neurotypical people but do not work for those who neurodiverse e.g. Autism and dementia. Adapted pain scales needed. Tazmin has created an example of this.</p> <p>Some neurodiverse have high threshold for pain and others low.</p> <p>Interoception training can help professionals know if the individual is hungry, thirsty and tired as well as in pain. This helps them to learn what communicative behaviours may be.</p> <p>Many examples of neurodiverse people being misdiagnosed and treated incorrectly. Examples include a man with liver failure given anti-psychotics and a woman with normal vital signs refused admission yet had pneumonia. Broken bones are also missed when individual has high pain threshold. Personally Tazmin has experience of misdiagnosis due to high pain threshold. Some pros think autistic people are violent when they are in pain.</p> <p>Interoception training and skills should be widespread and in line with annual health checks as a way to improve care. Lancaster PB also raising this issue.</p>	<p>Further discussion on this topic at next PB (ensure at least 20 mins on agenda)</p> <p>Tazmin Hook to send e-copies of presentation to NK for distribution</p> <p>Tazmin Hook to attend the study day on October 10th at RCHT (invite from Jane Rees)</p>
5	<p>AOB</p> <p>HD Lyndhurst Day Service in Bodmin is to have its' opening hours cut by 2 days.</p> <p>NK CC has made a statement which includes that all</p>	<p>Update at next PB</p>

	discussions so far have been internal. There are diminishing resources available within Adult Social Care. There are less people attending Lyndhurst Day Centre and CC are exploring the idea of reducing hours. Meetings with families will be held by the end of the month.	
	NEXT MEETING DECEMBER 18th 10.30-12.30pm Refreshments 10am	White Hart Hotel 2-3 Church Street St Austell, PL25 4AT