



MEETING NOTES:	Autism Partnership Board
DATE:	18 th 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 (ECA)	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 (EC)	NHS Kernow children's' commissioner
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	Organisation
Paula Volkner	KCCG
Rob Rotchell	Cornwall Council
Fiona Whitehead	Parent
Graham Wilkin	Cornwall Council
Tim Francis	KCCG
Richard Sharpe	Cornwall Council
Helen Childs	KCCG
Mel Wiesel	Cornwall Council
Michell Lobb	Parent Carer Cornwall
Rose Taylor	Volunteer Cornwall
Zoe Cooper	RCHT

Item	What was discussed?	Action
1	<p>Last meetings matter arising and PB update</p> <ul style="list-style-type: none"> - More service users and carers will be recruited to the PB. New Co-Chairs. 1 self-advocate and Cllr Jacque Gammon who 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 at next meeting - 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 	<p>NK to circulate</p> <p>NK to give updates</p>
2.1	<p>Action plan from the 2010 National Autism Strategy</p> <p>NK: Puts legal obligations on local councils and NHS. It contains the recommendations below. SC gave replies as to how Cornwall is working on achieving these goals.</p> <p>Each County:</p>	

	<p>MUST have an autism lead</p> <ul style="list-style-type: none"> - None identified as adult Lead in Cornwall. SC was fulfilling some of the role but will shortly move post <p>MUST develop a plan for how they will commission local services for adults and commission services considering local needs</p> <ul style="list-style-type: none"> - PB: not sure this is happening <p>MUST provide autism awareness training for all staff and specialist autism training for key staff including GPs and community care assessors.</p> <ul style="list-style-type: none"> - 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) <p>MUST appoint a lead professional for diagnostic and assessment services and ensure there is a clear pathway</p> <ul style="list-style-type: none"> - EC/RB/AS: Pathway is not at all clear in adults. - There is a Children's health <i>commissioning Lead (Liz Cahill) and diagnostic Lead (Sue Newman)</i> But no overall single lead across education, health and social care. - RJ: is Lead for Outlook SW Aspergers assessment service. - Diagnostic pathway is unclear for clients who have a query of ASD and also have a diagnosed learning disability or who have mental health issues falling under secondary care. <p>MUST improve the transition process and should have transition procedures in place for those using mental health services.</p> <ul style="list-style-type: none"> - EC: Transition in place now in many services, with the expectation is that NHS Kernow will commission from 0 up to 25. - RJ/AS/RB, RJ: Young adults in transition fall between Outlook SW and CPFT and don't get MH mainstream services. EC the MH condition has to be diagnosable and not sub- threshold e.g. low level anxiety. T RJ/AS/RB/ EC Some disagreement between CFT and Outlook SW around who carries out assessments for who, especially adults with MH issues on top of an ASC diagnosis. - RJ: It is not necessarily just young adults but adults of all ages can have difficulty currently accessing suitably adapted mental health support from secondary care services. 	<p>Nuala to contact CC who will fill the post of Autism Lead and NHS/CC commissioning lead.</p> <p>SC/SE to find out more</p> <p>External Meeting TBC Outlook SW NHS Kernow, CFT.</p>
2.2	Cornwall Council Autism Working Paper Action plan. SC reminded the Board that Cornwall Council Autism Strategy remains a working	

	<p>document and changes can be made.</p> <p>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>Here are the pages:</p> <p>Autism Information Cornwall A one stop hub for information, events and news - https://www.facebook.com/AutismInCornwall/?ref=br_rs</p> <p>Women with Autism/Aspergers: Cornwall UK - A group I opened last year https://www.facebook.com/groups/169481970270498/?ref=br_rs</p> <p>Autism/Aspergers: Cornwall UK - mixed gender group just launched https://www.facebook.com/groups/2233688863530625/?ref=group_browse_new</p> <p>40 years + HFA/Asp Cornwall Social and Meet Up Group - https://www.facebook.com/groups/294477824708499/?ref=br_rs</p> <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 www.supportincornwall.co.uk 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>ECA to email Debi Lewis</p>
3	<p>What happens next with Action Plan See: Action plan update (Appendix 1)</p> <ul style="list-style-type: none"> - 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. 	<p>EC/AK/RJ to provide organisational chart</p> <p>Invite member of the ASDAT</p>

	<ul style="list-style-type: none"> - EC: Sue Newman ASDAT lead works with Jo Lewis (RCHT). Liz Cahill commissioning. All children soon to go through single NICE-compliant diagnostic pathway. Part of the One Vision plan. Rest of PB not aware that this is happening and would like a full update. EC suggested inviting them to present to the PB. - EC: Most people with autism diagnosed in childhood. There is a push away from unnecessarily diagnosing children with ASC as it over medicalises their condition. They will still be put on the SEND register in their school. A diagnosis could prevent them getting jobs. GT this is unlawful under the Equalities Act. AK ASC is not a medical condition, it's a neurological difference. - EC: Young people who previously would have been at the bottom level (4) of statements are unlikely now to qualify for EHC Plan as the threshold is higher under the Children and Families Act. But you don't need an EHCP to get support. 55% of schools do buy in to support - RB/TH/HD/AS: when did this pathway begin? EC did not clarify. - 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. - AS/RJ: Telling parents that an ASC diagnosis causes stigma, it is a dangerous thing. Pressure will also be put on Education services. - RB: concerned that Cornwall is not using national guidelines to diagnose LD. 	<p>team to Sue Newman to meeting.</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> <ul style="list-style-type: none"> - NK: Due to late running of the meeting this presentation will be shortened. Apologies given. TH agreed to go ahead with the presentation. - Pain scales used for neurotypical people but do not work for those who neurodiverse e.g. those with Autism or dementia. Adapted pain scales needed. Tazmin has created an example of this. - Some neurodiverse have high threshold for pain and others low. 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. - 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 	<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</p>

	<p>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 profs think autistic people are violent when they are in pain.</p> <ul style="list-style-type: none"> - 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. 	October 10 th at RCHT (invite from Jane Rees)
5	<p>AOB</p> <ul style="list-style-type: none"> - HD: Lyndhurst Day Service in Bodmin is to have its' opening hours cut by 2 days. - NK: CC has made a statement which includes that all 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. 	Update at next PB

NEXT MEETING

March 19th 10.30 - 12.30pm Refreshments 10am

Truro Community Library, Union Place, Truro

ACTION LOG

Item	Action	Responsible	Update
1	Circulate role description for self-advocate chair	NK	Working Group continues to meet. New Terms Of Reference currently in 2 nd draft. When that's complete a role description and recruitment process will be agreed. Completion date: end February
2.1	To identify the Council Autism Lead and who has commissioning responsibilities.	NK	Stuart Cohen, with previous responsibility for autism commissioning has been seconded to NHS Kernow. An interim replacement has been recruited with a likely start date mid-January.
2.1	To find out what plans there are for training	SC/SE	Outstanding. Await comment from SE, NHS Kernow commissioning Lead for LD.
2.1	Lead from diagnosis in transition services to adults not clearly	SE/JT Outlook SW	Outstanding A meeting between the different services is to be arranged with feedback to next PB.

	understood by the PB or between professionals attending		
2.2	Facebook groups set up by TH/HD. PB would like the link to them.	HD/TH	Links provided in body
2.2	Scripts in use at CC for those with an ASC to use when enquiries made by phone. PB would like to know if any plans to create new ones	ECA	Outstanding ECA to contact Debi Lewis at CC
3	There is some confusion amongst professionals about : which pathways are used who is entitled to an assessment, how the ASDAT team work.	EC/RJ/AK	Outstanding Organisational chart to be produced EC/RJ Invite to Sue Newman to come to next meeting NK
4	Presentation on Interoception and pain	TH	Outstanding e-copy of presentation to be distributed