

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

# **ATTENDANCE**

Name	Position	Organisation	
Mike Hooper (MH)	Partnership Boards Officer	Healthwatch Cornwall	
Andrew Gray (AG)	Self Advocate		
Anne Passmore (AP)	Patient Experience Lead	Cornwall Partnership NHS	
		Foundation Trust	
David Allkins (DA)	Revenue and Benefits Admin Assistant and Self Advocate	Cornwall Council	
Dina Holder (DH)	Community Engagement Manager	The Women's Centre	
Ellie Craggs (EC)	Diva	The Women's Centre	
Heather Davison (HD)	Parent Rep / Self Advocate	PCC	
Jane Rees (JR)	Manager, Learning Disability & Autism	Royal Cornwall Hospitals	
` ,	Team	NHS Trust	
Katy Hutchinson (KH)	Director	The Chaos Group	
Kelvin Yates (KY)	Commissioning Manager	Cornwall Council	
Lisa Ling (LL)	Approved Mental Health Professional	Community Mental Health	
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		Cornwall Rural Community	
	,	Inclusion Matters	
Natalie Brown (NB)	Social Prescribing Health & Wellbeing	Pluss	
N. 11.0 ( (110)	Project Support		
Neil Oats (NO)	Self Advocate		
Nicky Hancocks (NH)	Trainee Psychlogist	Outlook South West	
Rachel Brown (RB)	Clinical Psychologist and Manager	Spectrum	
Rebecca Jelbert (RJ)	Clinical Psychologist Adult Aspergers	Outlook South West	
	Service		
Richard Gittens (RG)	CHAMPS	Cornwall Council	
Shelagh Mitchell (SM)	Liaison Lead for Learning Disability and Autism	Cornwall Council	
Tigger Pritchard (TP)	Autism and PDA Advocate, Consultant and Trainer	National Autistic Society Cornwall	



# **APOLOGIES**

Name	Organisation
Anne Bowdler	Cornwall Partnership NHS Foundation Trust
Chris Burns	Self Advocate
Colin Blandford	Cornwall Council
David Allkins	Cornwall Council
Gemma Dyson	Outlook South West
Ginette Trewren	Cornwall Council
Helen Childs	Kernow Clinical Commissioning Group
Councillor Jacquie Gammon	Cornwall Council
Julie Attwell Cook	Cornwall Council
Katherine McQuay	Cornwall Council
Kerry Crawley	Cornwall Council
Lerryn Hoss	Royal Cornwall Hospitals Trust
Melanie Wiezel	Cornwall Council
Nory Menneer	Kernow Clinical Commissioning Group
Sarah Stevens	Pluss
Sarah Thorneycroft	Cornwall Council
Tim Francis	Kernow Clinical Commissioning Group
Vicki Allen	Cornwall Council



# **ACTION LOG**

DATE	<u>ACTION</u>	RESPONSIBLE	<u>STATUS</u>
17/12/2019	RB & RJ to draft a letter on behalf of the Board stating the need for an Autism Lead for Cornwall. MH to determine all addressees.	RB/RJ/MH	Ongoing.  Delayed due to transfer of diagnostic services.
17/12/2019	Circulate information on Positive People and other relevant work of Pluss.	NB/MH	Complete.
17/12/2019	Update from Cornwall Council day services transport.	МН	Ongoing. Update to March 2020 meeting.
17/12/2019	Organise Adult Autism Strategy task and finish group.	KY/MH	Complete. Group meet on 24 March 2020.
17/12/2019	Email Cornwall Link and Inclusion Matters flyers to the Board.	МН	Complete.
17/12/2019	Investigate suitability of jigsaw puzzle symbol.	МН	Ongoing.
17/09/2019	Commissioning Team to provide an update on the Day Services consultation to the next meeting of the Board.	BS	Ongoing. Presenting 17/12/19.
17/09/2019	Invitation to Dr Shankar to attend the next meeting of the Board.	NK	Ongoing. Clarification required regarding what information the Board seeks.
17/09/2019	Raise the ongoing difficulties with diagnosis and assessment with Paul Cook.	NM	Outstanding. Delayed due to transfer of diagnostic services.
17/09/2019	Help to publicise CHAMPS events.	NK	Complete. CHAMPS information is sent to Enquiries@healthwatchcorn wall.co.uk and forwarded onto the Boards
17/09/2019	Invite KY to attend the next meeting of the Board to discuss the Adult Autism Strategy.	NK	Complete Presenting 17/12/19



17/09/2019	Meet with Councillor Jacquie Gammon to raise concerns for people with mental health issues.	NK	NK/MH met Cllr Gammon on 31/10/19
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
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	Ongoing.  17/09/19 Await JJBM re-placement  17/02/20 Sgt K Silver - the lack of Police engagement is a result of internal staffing issues. Once staff are in place, please rest assured we are all very keen to get back to working closely in support of all the organisations we support.
20/06/2019	KY to meet with CC/KCCG commissioners as part of integrated adults and children's autism strategy.	KY	17/12/19 Work being undertaken to align Adult and Children's Strategies. Draft Adult Strategy T&F Group agreed.
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 phoneline 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	Welcome, introductions and apologies	
	There were round table introductions.	
2	Minutes and updates from previous meetings	
	The minutes of the meeting of the Board held on 17 September 2019 were agreed as a true record.	
	Progress on issues raised at previous meetings was noted.	
3	Updates from around the table	
	MH 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.	
	New Carers Strategy	
	KY reported that the process of developing a new Carers Strategy had begun ahead of the end of the current commissioned services, which would run until June 2021. He would ensure that the Board was engaged and its views sought throughout the process.	
	Spectrum	
	RB provided background as to the information and signposting role of Spectrum, including engagement with individuals to develop bespoke plans based on their personal goals and the promotion of positive health and wellbeing. Around five or six calls a day were received regarding aftercare.	
	RB suggested that the Board should champion the need for an Autism Lead for Cornwall, a statutory responsibility under the Care Act 2009. Key issues were to:	RB & RJ to draft a letter on behalf of the Board stating the need for an Autism Lead for Cornwall.
	address the three year waiting list for diagnosis;	MH to determine all
	<ul> <li>ensure that statutory and health services at all levels were educated in autism, as per the Autism Act and the Care Act;</li> </ul>	addressees.
	<ul> <li>ensure that autistic people received adequate mental health services across age ranges (Children and Adolescent Mental Health Services and Community Mental Health Teams had no autism specificity);</li> </ul>	
	ensure that reasonable adjustments be made consistently	
	<ul><li>across the health and social care sectors; and</li><li>increase the number of follow-on services in the county.</li></ul>	
	Holifield Farm Project	
	AG drew attention to the work carried out by the Holifield Farm Project, encouraging people to look into the courses that it	



offered. He intended to start to support groups there in the new year.

#### **Pluss**

NB provided the background to Pluss, a social enterprise that aimed to encourage and create access to work for people with disabilities and other disadvantages.

Positive People aimed to help individuals out of work to develop the necessary confidence and skills to find employment through personally tailored programmes. Further information could be circulated following the meeting. NB to send MH information on Positive People and other relevant work of Pluss for circulation to the Board.

#### Divas

DH reported that Divas 2 was ready to be rolled out, with training scheduled for the new year. It would offer opportunities for 16-25 year olds and would focus upon consent and healthy relationships.

The DIVAS had presented at the Rape Crisis England and Wales National Conference earlier in the month.

DH had been contacted by Dr Clare Gunby, Research Fellow at the University of Birmingham, who was leading a research project, funded by the National Institute for Health Research, entitled 'Supporting survivors of sexual violence: a mixed methods, co-research study of the role, funding and commissioning of specialist services provided by the voluntary sector in England'. The three-year project aimed to fill gaps in evidence. For example, currently there was almost no evidence about the role of the specialist voluntary sector in providing sexual violence services, despite their important role in provision and innovation. There was also a lack of evidence about how specialist voluntary services worked with and alongside statutory services. Further details about the project could be found at:

https://www.fundingawards.nihr.ac.uk/award/18/02/27

Researchers were currently liaising with key providers and commissioners of sexual violence services in both the voluntary and statutory sectors in order to get context and inform the questions for two national surveys. DH would be participating in a telephone interview to share her knowledge.

# Carers Awareness Study Day

JR reported that carers, care workers and family members and all relevant agencies had been invited to a recent study day at Treliske. The attendance level had been disappointing but good feedback had been gained. It was intended for an event to be held six-monthly, with the next being in June/July 2020. KY suggested that invites could be sent through Kernow Carers Service. JR invited people to contact her at <a href="mailto:jane.rees5@nhs.net">jane.rees5@nhs.net</a> if they could assist with publicising future events.



#### **Sexual Health Services**

SM raised concern that it appeared that expertise had been lost since the transfer of sexual health services from RCHT to Brook, with no apparent handover links. She would be meting with a public health consultant to work together and to organise training.

#### **Carers Support Workers**

KY reported that a Carers Support Worker role was to be piloted for a 6 month period. There would be two staff in place who would wear easily identifiable uniforms and would help to prepare patients for discharge and their ongoing journey.

#### National Autistic Society (NAS)

TP reported that the NAS was attempting to increase its work in Cornwall, having previously been very active but having seen a decline in recent years. Attendees were encouraged to join the new facebook page, on which "anything and everything" was shared.

TP hoped to be able to regularly attend future Board meetings and to bring London based representatives. He now operated mostly out of Bodmin, having previously been predominantly Redruth based.

He was looking to hold conferences around the county in order to promote the work being carried out and the services on offer from the wide range of organisations across Cornwall.

#### **Day Services**

HD stated that there was a lack of accessible day services for adults and that there was a gap that meant that high functioning adults fell "out of the loop". An update was required regarding future day services transport as the current minibus contract was due to expire in March 2020.

# Outlook South West (OSW)

RJ said that OSW provided a diagnosis service for aspergers and high functioning autism for adults (from 16 years of age), providing a bridge for those without access to secondary care services.

Currently, demand far outweighed supply, with over 400 referrals against a target of 140 and a two year waiting list. Proposals for additional monies had been proposed but funding across services was finite.

It was recognised that the two year waiting list created problems in itself as the needs of individuals could change massively over such a period.

MH to seek update from Cornwall Council day services transport.



	RB reiterated the need for an Autism Lead for Cornwall (see Spectrum update, above).	
4	Adult Autism Strategy	
	KY opened by addressing previously raised concerns, stating that the focus on autism had not been downgraded when the previous work towards developing a strategy had been amended to a working paper.	
	He was working with Mandy Owen, lead for the Young Peoples Strategy, to bring that and the new Adult Autism Strategy (AAS) into sync, both in terms of presentation and of streams.	
	It was acknowledged that some actions included within the action plan had not been met. There was a need to deconstruct it to address the numerous overlaps within it and it was recognised that all actions should be accompanied by clear criteria and that progress against them should be detailed.	
	KY proposed that a working group be set up to consider the draft Strategy with a view to getting agreement from the Board and feeding up into the Council's decision making process. KY would email details of and proposed dates for an Autism Strategy working group to MH, who would then circulate the information to the Board and invite participants.	KY/MH to organise Adult Autism Strategy task and finish group.
5	Update on Day Services	
	Katy Hutchinson of The CHAOS Group provided an update on the Day Services consultation.	
	Cornwall Council had commissioned StayatHome Cornwall, part of The Chaos Group, to act as an independent facilitator to engage with service users and their families to gauge their views and to help to shape how services would look in the near future.	
	In addition to the 500 completed surveys and the hundreds of face to face conversations that had taken place earlier in the year, seven events had taken place across the county through late October and November.	
	A co-production session to talk about how day services could look and to enable service users to have their say in creating the changes that they want would be held at the Community Library, Union Place, Truro TR1 1EP between 10.30 am and 12.30 pm on Thursday, 9 January 2020.	
	SM reminded the Board of the CHAMPS Christmas flu jab song, which could be found on YouTube.	
6	Inclusion Matters Project and Aspergers support in Cornwall	
	Naomi Gorvin introduced herself. She had recently taken up the position of Community Asset Worker for Cornwall Rural Community Charity, with a focus upon the new Inclusion Matters	



Project. As part of the role she would be identifying gaps in community support provision in terms of community support groups and helping groups to develop and to become more resilient.

It appeared that there was a lot of voluntary support available but that it was not always being accessed as people didn't know how to. NG said that there would be a massive recruitment drive for individuals with Autism and Aspergers to volunteer and asked if members of the Board could help her to identify the support for Asperger's and Autism that was currently available within the county.

### Attendees stated the following:

- There was a need for such information to be collated and for opportunities to be promoted as there was a clear lack of awareness of what was available.
- Holifield Farm, a community project based in Gweek, focussed on Day Opportunities for adults with additional needs.
- The Go Forward events held at All Saints Church Communty Centre offered mental health support.

NG urged everyone to sign up to Cornwall Link at https://cornwall-link.co.uk/ and flvers on Cornwall Link and Inclusion Matters were circulated (MH would circulate electronic copies with the minutes). Cornwall Link was a website on which information could be found on a wide range of services, community groups and organisations in Cornwall and the Isles of Scilly. It aimed to provide individuals, families, carers, volunteers and healthcare professionals with access to services and community based activities in order to reduce social isolation and improve health and wellbeing.

The details held on Cornwall Link were checked and updated every six months to ensure that information was accurate.

MH circulated information on Ask Cornwall, a digital community platform connecting people in conversation around health and wellbeing, managed by Healthwatch Cornwall & Isles of Scilly. It could be accessed at https://askcornwall.co.uk/, where a promotional film showing how Ask Cornwall could make a difference could be viewed.

MH to email Cornwall Link and Inclusion Matters flyers to the Board.

#### 7 **Any Other Business**

### **EU Settlement Scheme**

KY reminded the Board that, following Brexit, EU, EEA or Swiss citizens could apply to the EU Settlement Scheme to continue living in the UK after 30 June 2021 at:

https://www.gov.uk/settled-status-eu-citizens-families



# **Autism Partnership Logo**

TP raised concern about the Autism Partnership logo included on the agenda, a St Pirans flag incorporating the Autism jigsaw puzzle design, stating that there had been subtle cultural changes on a global level that people should be respectful of in order to not cause offence.

Responses to the issue were mixed, with many pointing out that it had been designed by a service user and that it should be retained whilst others suggested that the infinity symbol could be adopted.

MH to investigate the suitability of Autism puzzle symbols.

MH undertook to look into the matter.

<b>NEXT MEETING</b>	10.30am - 12.30pm
DATE	Tuesday 17 March 2020
LOCATION	Truro Community Library, Union Place, Truro TR1 1EP