

Minutes of the West Sussex Autism Partnership Board (APB)

Meeting: 10 July 2025 11am – 1pm (zoom)

Attendees:

Diana Bernhardt - Commissioning Service Manager, WSCC - Chair Gary Capelin - Peer Support Co-Ordinator, WSCC Simona Giunta - Commissioning and Contracts Officer, WSCC - Minutes Tom Elsam - Service Manager Lifelong Services, WSCC Andrew Cole - General Manager Learning Disability and Neurodevelopmental Service Jess Dare - Deputy Clinical Lead Talking Therapies SCFT Katie Low – Venture People Jayne Simpson – Parent carer Martin Ford – LIMA Aldingbourne Trust Katie Green – Access All Areas Sam Rogers - Deputy Head of Mental Health and Children and Young People's Commissioning and Transformation (joined later) Alison Waters – NDP Lived Experience Advisory Panel, Community Manager

Graham Sargeant - ASSA

Anna Lansley – ASSA (first half)

Guests:

Stuart Gibbons, Deputy Director Childrens (WSCC)

Apologies:

Sheryl Bunting – West Sussex Carer Support Maggie - Aspective Dan Gregory - Aspective Vicky Littlejohn - ASSA

Welcome and Introductions

Diana welcomed all, noted apologies and introduced guests at the meeting.

Last meeting notes

May 2025 notes agreed. Action: Simona to upload to the website

Actions from the previous meeting completed.

Autism Strategy update: Diana attended the WSCC Adults Departmental Leadership Panel (DLT) on 09 July 2025 with the Autism Strategy. The strategy will go to Children's DLT next week. It will also be shared within WSCC and with the Integrated Care Board (ICB) and the plan is to present to the Health and Wellbeing Board in December.

A member asked the timeframe for sign off. Diana said this is likely to be Health and Well-Being Board in December. The delay to December is positive as it gives time for the document to be considered by more senior people which is crucial to achieving support and interest from senior officers and other professionals.

1. Creating an All Age Autism Partnership Board

Diana met with lived experience members of the Board who fed into the slides presented at the meeting. Diana asked the meeting to provide feedback on the slides

What strengths about the existing membership do you want to continue with?

Q: Is it possible to have regular representation from those in the NDS who are directly involved with customers as well as managers?

A: The NDS attends and contributes to several forums and meetings around the county to ensure they are part of conversations. Andrew confirmed he will attend the APB regularly and was happy for NDS staff attendance to be reviewed as part of the APB review work.

What needs to be different about membership of the board? (slide 5):

 Suggested to extend APB membership to include Further Education colleges and providers as well as SEND program

How could we make changes to the board? (slide 6):

• Diana will coordinate developing a self-assessment questionnaire and would like people from the existing board to be involved. Martin said he was interested in taking part.

- Noted It was also suggested this can also be taken to the Local Authorities autism meeting to seek feedback on learning from other authorities.
- Email will be sent following the meeting to see if other APB members not able to attend would be interested in taking part. Anyone other than members who would like to be involved, please contact LLScommissioning@westsussex.gov.uk

What helps making meetings more accessible? (slide 7):

 Diana explained that all other council and health meetings are on Microsoft teams. The zoom software is not supported and therefore this makes it more difficult to use. However, it is acknowledged that Zoom has historically been preferred platform for APB members. Two members shared recent experiences of Teams: one was positive and one negative.

Action: Try test runs for hybrid meetings using Teams and see what lessons we learn as a group.

Action: any APB members who do not currently have access to Teams, contact <u>LLScommissioning@westsussex.gov.uk</u>

- Suggestion to take this question re accessibility to the Lived Experience Advisory Group for their exploration
- Learn from Customer and Carer group who have successful hybrid meetings.
- A bigger membership may not be inclusive to those with lived experience and those who may experience sensory overwhelm.
 Noted a member suggested keeping membership maximum to 25 and not 30. It is important that people's voices are heard and for individuals to feel comfortable within the group.

Action and next steps: Feedback on the slides and above comments will be used to draft new Terms of Reference and to be presented at the September 2025 Board.

2. Neurodevelopmental Service update. Andrew, Alison and Sam presented. Some key points from the slides:

Neurodevelopmental service provided by SPFT

- Team of 5 staff
- Currently 3665 people on WSCC waiting for an autism diagnosis.

- Team currently working with 37 live cases
- NDS receives an average of 50 referrals per month
- Prioritisation of cases is done via RAG rating (Red Amber Green): currently 74 Red, about 1000 Amber and the rest Green.
- Service only provides autism diagnosis.

The Transforming Care Autism Team (TCAT)

Specialised multi-disciplinary team of 11 people covering Sussex. Its aim is to avoid hospital admissions. Support from TCAT only after formal diagnosis.

Neurodevelopmental programme

Focus of the program is Autism Spectrum Condition (ASC) and Attention Deficit Hyperactivity Disorder (ADHD).

- Lived Experience Advisory Panel (LEAP) meetings happen on 3rd
 Tuesday of every month: get in touch with Alison if you're
 interested or have any questions <u>alison.waters7@nhs.net</u>
- Neurodevelopmental programme aims to develop a solution to demand and waiting lists through a different, joined up approach based on resources available.

Member shared how they participated in a LEAP Consultation session with the Musculoskeletal (MSK) Community Days physio lead and gave feedback on how the Community Days could be more neurodivergent friendly and what adjustments could be made. It was good to see the suggestions made from this session were implemented at the following MSK Community Day.

Q: Re TCAT Team involvement – the member's experience of the Team was good. However, it was after the Team's involvement ended that they felt it was disorienting, as a carer, not to have that support any longer. A: Andrew commented the TCAT involvement is temporary to allow more people to be seen and supported and for it to be a sustainable resource. Noted re support to carers.

Q: Re therapeutic Services. WSCC Operational Services support a lot of people at high risk to themselves generally through lifestyle choices or behaviour, who are not receiving any therapeutic support. Teams have nowhere to refer customers who do not have diagnosed mental health issues. This in turn causes a cycle of increased levels of support to

manage the risk and customers who become more triggered by it. A: there is a piece of work currently going on regarding community therapy referrals. **Action:** Sam will invite Tom and Katie to join that forum.

Q: Re Waiting list for diagnosis. Member commented how it feels as if NDS have given up in trying to clear the backlog. A diagnosis is the gateway to benefits and workplace adaptations. Technically it is not needed but practically for many it is what gets them the support they need depending on the employer.

A: It's support irrespective of diagnosis – it is a way of working that is part of the bigger Pathway Pilot work. It does not replace the assessment process but it's a tool to support people - people have said they need the support.

Another thing to explore is how other professionals can undertake diagnostic work. Not every referral needs the specialised NDS input – we want to try different approaches to meet different needs of the population, some elements will work for some, and other elements will work for others.

3. Pulling this together and next steps

Draft new Terms of Reference will be main topic at September Board.

4. AOB

None

Actions agreed:

Action	Who by	Timescale
Publish May 2025 minutes	Simona Giunta	Aug 25
APB members who do not currently have access to Teams, contact LLScommissioning@westsussex.gov.uk	Members	Aug 25
Test runs for hybrid meetings	Gary Capelin	Sept 25
Email board members to ask if other people want to be involved in developing self-assessment questionnaire.	Simona Giunta	July 25

Draft a new Terms of Reference and present it at the September 2025 Board.	Diana Bernhardt	Sept 25 Board
Invite Tom Elsam and Katie Low to community therapy referrals forum	Sam Rogers	Sept 25

Date of next meeting:

25 September 2025 11am - 1pm (online, Zoom)

Zoom link will be circulated 2 weeks prior.