



West Sussex Autism Partnership Board (APB)

Meeting: 20 February 2025, 11am – 1pm (zoom)

Attendees:

Diana Bernhardt – Commissioning Service Manager (WSCC) Chair
Simona Giunta – Commissioning and Contracts Officer (WSCC) Minutes
Katie Glover WSCC - Commissioning Manager
Tom Elsam WSCC - Service Manager Lifelong Services
Cole Andrew – NHS Neuro Developmental Service
Jayne Simpson – parent carer
Sheryl Bunting – West Sussex Carer Support
Maggie – Aspective
Katie Green – Access All Areas
Maxine Harcourt-Kelly - parent carer
Vicky Littlejohn - ASSA
Graham Sargeant - ASSA

Guests: Georgia Harper – Autistica

Apologies: Martin Ford – LIMA project

Dan Gregory – Aspective

Welcome and Introductions

Diana welcomed Georgia Harper from Autistica who attended the session to present Autistica's work.

Last meeting notes

November 2024 notes agreed. Action: Simona to upload to the website

1. Matters arising

There is an outstanding action to circulate information on the community hubs, which will be actioned after the meeting. All other actions complete.

2. Autistica presentation

Georgia Harper – Autistica Policy Manager

Autistica made Freedom of Information requests to all 42 Integrated Care Boards in England. Waiting times for assessment in some parts of England stand at 5/6 years. West Sussex waiting times are at an average of 1.5/2 years.

Q: What do you do to represent all people on the spectrum, not only the high functioning individuals?

A: This is something we want to improve. A third of the team at Autistica are neurodivergent. We are funding some research into anxiety levels of autistic people who struggle to speak and/or are non-verbal

Q: Are you using Autistica's own Employer's Index?

A: That is the longer-term aim. The initial focus was to set it up.

Q: With regards to goal 3 in your presentation, anxiety. There was a study on Interoception in autistic people that started with autistic people and was later opened to a much wider spectrum. How does Autistica ensure these studies are truly aimed at autistic people?

A: We often see that studies need to pass various stages of feasibility testing to attract funding and a lot of the time widening the research ensures funding is secured. However, there are things that benefit autistic people that will also benefit the wider population.

Q: What about people who no longer have living parents or are not in touch with them? Diagnosis relies on information that is difficult to get.

A: We are aware of this challenge. It is something Autistica would like to see changing.

Q: Is anything being done to promote the Right To Choose option for faster diagnosis?

A: Right To Choose is often a more feasible route and we do mention this in our assessment work. However, we also know this is not a substitute for the wider reforms needed in the assessment system. Waiting lists for some Right To Choose providers are now also backing up. Integrated Care Boards will soon be allowed to set a limit on how much they are willing to pay out for. Right To Choose option is still a national right, but it may mean people have to wait longer to be seen by a Right To Choose service than they do currently.

3. Autism Strategy Workshop - Katie Glover – WSCC

Katie provided an update on the work to develop the strategy. 800 people were reached during consultation stage. A half-day workshop is scheduled for 25 Feb 2025; members who want to explore these areas more are welcome to join and participate.

Areas of focus identified through the feedback:

- Public and community awareness and understanding
- Early help and support in schools
- Pathway around diagnosis
- Knowing what support is out there and where to get help
- Training and learning and development around autism of “helping” staff
- Access to and autistic appropriate mental health support
- Social connection and access to social opportunities
- Support around transition to adult life including support around things like employment, housing etc.
- Support for parents and unpaid carers – including whole family approach
- Co-production around the above

During the workshop members were asked for their opinions and reflections on the above areas underlined.

Feedback from members included:

- It's important to remember that all autistic individuals are different and all individual. Professionals need to get to know the person. Planning-wise this could mean raising awareness, looking at the training that staff get and autistic people talking about their experiences.
- The majority of carers do not have autism training – commissioning are currently developing new contracts for Supported Living Framework and other services and this requirement could be incorporated.
- There could be different levels of training depending on employees' roles

- Making adjustments to the sensory environment, not just training staff. Being aware of sensory overload and how it affects autistic people
- Issuing reminders to providers to train new staff as there is a high turn over of staff in this field.
- It would be good to have a shorter pathway to diagnosis, a lot of the time services are working with individuals who suspect being autistic, but they may have a different issue with social functioning. Shorter pathway would ensure people receive the right support.
- Diagnosis waiting list in West Sussex is 3500. NHS has a finite number of staff to progress and process this. It would be good to consider a wider West Sussex response e.g. primary care helping with diagnostics. Also consider if a triage of needs on waiting list could support to prioritise individuals. The APB could be an important voice to advocate for this wider partnership work.

Action: Diana to follow-up with ICB and SPFT and arrange an item at a future APB.

- It would be good to highlight people's Right To Choose in West Sussex literature. This was noted.
- Are we commissioning the right care for people to feel less isolated? Plenty services are commissioned for people to access the community with support. There is a need for services to work with autistic people to increase confidence and skills in accessing the community and engaging with it.
- Pathfinder West Sussex is a good source of mental health support information. However, some people have been turned down by Improving Access to Psychological Therapies (IAPT) if they are engaged with Pathfinder. Sometimes individuals need support from more than one place.
- Re leisure centres – for these to be truly accessible and inclusive for autistic individuals, commissioning needs to embed inclusion expectations in contracts.
- Re employment – it would be good to have one place where autistic people can look at autistic-friendly employers and access support. Disability Employment Advisors (DEA) at the Jobcentre can only provide with emotional support and very little practical support. Employment services are not equipped to deal with autistic people who have degrees in terms of appropriate job options available.
- Re housing – a lot of autistic people struggle to share and are usually placed in shared accommodation which causes stress and escalates behaviour. This then becomes part of an individual's

behaviour and risk history. There is a need for placements with own front door at an early stage.

Focus on training and raising awareness with Social Landlords – a member shared they prefer to use email but usually get an email back referring them to a phone line. Support also needed for autistic people who own property to move to sell/buy a different type of property when their needs change later in life.

Members can email Katie or Diana with further comments and suggestions on all areas of focus. LLScommissioning@westsussex.gov.uk

A member asked if senior leadership will be attending the May 2025 APB in relation to the Autism Strategy work. **Action:** Diana to invite Assistant Director for Commissioning Tony Meadows.

The main agenda item at the next APB will be around agreeing an Autism Strategy Plan to round up the Strategy project.

Timeline

- April Steering Group: first draft
- May APB: updated draft
- June/July: Internal Council process
- September onwards: approval process

4. AOB

- A member asked about the Oliver McGowan training. It was confirmed that this course is mandatory for West Sussex County Council staff and Sussex Partnership Foundation Trust staff
- Aspective members asked whether the Council would support them to spend grant money received from Lottery – **Action:** Diana will make contact outside of the APB meeting to discuss this with Aspective representatives.

Actions agreed:

Action	Who by	Timescale
Upload November minutes to website	Meeting Administrator Simona Giunta	March 2025

Diana to offer follow-up meeting with Aspective	Meeting Chair Diana Bernhardt	March 2025
Schedule item at a future APB: Diagnostic Service update – work on diagnostic Pathway	Meeting Chair Diana Bernhardt	July 2025
Invite Assistant Director of Commissioning to May 2025 APB	Meeting Chair Diana Bernhardt	March 2025
Carried forward from last meeting: circulate information on the community hubs	Simona Giunta/Gary Capelin	April 2025

Date of next meeting:

15 May 2025 11am - 1pm (online, Zoom)

Zoom link will be circulated 2 weeks before the meeting.