



West Sussex Autism Partnership Board (APB) Minutes

Meeting: Thursday 29 February 2024, 11am – 1pm (online - Zoom)

Attendees:

Diana Bernhardt – Commissioning Service Manager (WSCC) Chair
Anna Lansley – ASSA, Aspie Trainer
Graham Sargent – ASSA
Vicky Littlejohn – ASSA
Dan Gregory – Asperger's Voice
Maggie – Asperger's Voice
Bodil Scrivens – Parent carer
Jayne Simpson – Parent carer
Sheryl Bunting – Learning Disability and Autism lead, Carers Support
Katie Green – Aldingbourne Trust, Action All Areas
Martin Ford – Aldingbourne Trust, LIMA
Jonathan Foley – Clinical Lead Time to Talk, NHS West Sussex
Matthew Moors – Public Involvement Lead for Virtual Wards and long-term conditions, NHS Sussex
Paul Wilmette – Interim Assistant Director, Adults and Health (WSCC)
Ed Armstrong – Commissioning Manager (WSCC)
Shannon Marchesani – Commissioning Service Manager (WSCC)
Simona Giunta – Commissioning and Contracts Officer (WSCC) Minutes
Gary Capelin – Peer Support Co-Ordinator (WSCC)

Apologies:

Lucie Venables, Katie Glover, NDS Service.

Notes and Actions

1. Welcome and Introductions

New attendees introduced themselves and apologies were recorded. Matthew Moors is the Public Involvement Lead for Virtual Wards and long-term conditions, NHS Sussex. Also involved in the Lived Experience Audit Panel (LEAP).

Paul Wilmette is Interim Assistant Director of WSCC Adults and Health Department (attending in lieu of Alan Sinclair)

Jonathan Foley – Clinical Lead Talking Therapy NHS West Sussex (attending in lieu of Jess Dare)

Martin Ford – Aldingbourne, LIMA

2. Actions agreed at last meeting

All complete. Simona to circulate yearly planner with minutes.

3. WSCC Interim AD Paul Willmette

Paul Willmette explained that he was attending in the context of APB members requesting the Director of Adult Social Care, Alan Sinclair to attend the Autism Partnership Board regarding funding decisions that affect autistic people and specifically in relation to the ending of the advocacy contract with Impact Initiatives in September 2023.

He reflected that WSCC, like other local authorities, are needing to operate within a challenging financial climate. The council are moving towards a model of more independent and self-sufficient services.

Council budget released recently: WSCC has gone into reserves this year. This is not something WSCC can do every year, as if this is the case the reserves would eventually run out and the council may have to declare bankruptcy.

WSCC also working on a general improvement plan and are likely to be inspected by CQC (Care Quality Commission) in the near future. Work is underway to prepare for the inspection and to take forward the improvement plan.

Member asked for a WSCC guarantee that a member of APB will be involved in decisions for autistic people and co-production in the form of a person attending meetings, not only participating in surveys.

It was agreed that APB is the right place for those conversations. WSCC should not make decisions without engaging in co-production and acknowledged that members were left out on the decision-making process and how the decision to terminate the contract was communicated last year. These concerns are acknowledged and WSCC wish to make this guarantee more explicit, for example through the Terms of Reference of the Autism Partnership Board.

Member felt that Sections 1,2 and 3 of the Care Act were not being fully discharged by WSCC with Prevention services, Connect to Support Website and statutory advocacy contract. These services are not fit for purpose for the self-advocacy groups and individuals' needs.

Council agreed to look at these concerns. WSCC's position is that those sections are fulfilled as it would be illegal to not do so. Members can provide a specific list of what elements of sections 1-3 they consider are not being fulfilled.

Member asked what consequences there would be for a council not fulfilling their duty under the Care Act. It was clarified that WSCC has to fulfil its obligation, and would consider any specific concerns that members identify.

The Council are using a different model of linking to community services and help people navigate other services with more autonomy.
Member commented that the argument of people being dependent on services and moving towards more independent services represented an ableist approach.

Member shared they had recently written to the Director of Adult Social Care about their concerns around co-production within the council. The response they received was to reassure that that WSCC are trying to do better.

It was confirmed that WSCC are looking to work with people and to find solutions together.

4. [LEAP presentation](#) – [Matthew Moors](#)

LEAP participants with lived experience will be paid.

Q: how will self-advocates be supported to contribute?

A: Public involvement lead will advocate for that support, including providing some training for individuals. Customers can attend the oversight board for the redesign of the Neuro Developmental Service (NDS).

Q: how will you ensure the whole spectrum is represented rather than only high-functioning autistic people?

A: a range of options will be available, not just a monthly meeting. We can use 121 conversations to ensure that we reach the wide user experience, working through the barriers to reach people. LEAP want to be inclusive and to ask 'who is not in the room?'

Users will lead LEAP and represent themselves with NDS.

Member: LEAP sounds good. Hopefully it reaches out to other organisations, looking out not only looking in.

Matthew: we're all different and everyone's experience is different. There will be LEAP **themes** that will come up and those are what needs addressing.

5. [Autism Strategy presentation](#) – Diana Bernhardt

Diana explained that Katie Glover, Commissioning Manager is leading on this piece of work but unfortunately is not able to attend meeting today.

The development of the strategy by WSCC are planning to coproduce an all age autism strategy with a year of engagement and coproduction to develop this in partnership with people who use services, family carers, providers and other stakeholders.

It is proposed to establish a steering group to coordinate the work. This is open to members of the autism partnership board but also others to ensure a wide representation across the range of needs.

3 strategies developed by other local authorities (Bromley, Surrey and Hackney) presented to seek members feedback on what the final strategy could look like.

Members questions and comments.

- the 3 sample strategies seem to have strong focus on employment. Does not match with member's experience of this service user group. Brighton and Hove strategy mentions MH, PH, Social isolation and not the higher needs like employment.
- The strategies do not mention the 30% people who are classical autistic who have also learning disability. Nothing about reducing social isolation or increasing community participation.
- Access All Areas at Aldingbourne could represent users that have higher/less functioning support needs.
- Steering group needs representation from other services. We need consistent and committed representation by NHS/ICB which is a lesson learnt from a previous steering group.
- 2024 Year of autism. Members expected to see many events about autism happening around the county as WSCC (Lucie Venables) had said this. WSCC are still committed to a Year of Autism.
- Parent carers can also represent the 30% of users with higher needs/low functioning.
- Advocacy could be arranged for other users to get their thoughts represented.
- Concerns expressed about self-advocates being able to participate in steering group without support.

Diana's feedback:

- all above points noted.
- priorities for strategy will be what is developed locally and will reflect all of those needs of different users.
- strategy will need to follow the Care Act and the national autism strategy.
- With regard to supporting the self advocacy groups, we are identifying what technology can be used to support the groups and are talking to individuals and the self-advocates groups about the support ending.

- WSCC will use their contacts with senior officers in NHS/ICB to ensure consistent representation in this piece of work.

6. AOB

- Member had submitted an FOI request which had been declined by WSCC due to time it would take to fulfil the request. Member appealed this through the Information Commissioner's Office, and it was upheld in their favour. Other members were grateful for this representation.
- Member asked for an extension to self-advocacy groups support given that the worker from Independent Lives was absent due to illness. The council agreed to look at this.
- Agreed that the last meeting to trial hybrid meetings from May. Members asked whether travel expenses will be paid. WSCC to confirm.

Actions agreed:

Action	Who by	Timescale
Circulate 2024/25 APB meetings planner	Meeting Administrator Simona Giunta	March 24
Seek to include guarantee of co-production in T of R of APB	Paul Willmette	May 2024
Email LLS Commissioning email to express an interest in the Steering for Autism strategy Group.	Members	May 24
Confirm if WSCC will reimburse expenses for travel to Chichester venue for customers	Diana Bernhardt - Service Manager Commissioning	April 2024
Explore whether an extension to the support to the self-advocacy groups can be extended.	Paul Willmette	March 24

Dates of next meeting:

23rd May 2024, 11am - 1pm

Venue Hybrid, online and WSCC Chichester County Hall

Zoom link will be circulated in early May