



## West Sussex Autism Partnership Board minutes

**Meeting:** Thursday 22nd July 2021, 11am – 1pm (online Zoom)

**Attendees:**

Lisa Loveman (Chair) – Commissioner (WSCC)  
Anna Lansley – ASSA; Aspie Trainer  
Jayne Simpson – Parent carer  
Tracey Ferris - Impact Advocacy Supporter for Aspergers Voice  
Andy West – Impact Advocacy Supporter for ASSA  
Martin Ford – Aldingbourne Trust (manager of My Network & LIMA services)  
Mike Smith – Project Manager Commissioning Team (WSCC)  
Roxanne Hall – Asperger’s Voice  
Dan Gregory – Asperger’s Voice  
Mark Bushby – Independent advocate  
Graham Sargent – ASSA

**Guests:**

No invited guests

**Apologies:**

Warren Ball – Autism Specialist (SPFT)  
Joel Benson – ASSA  
Pete Ring - ASSA  
David Henderson – ASSA  
Bodil Scrivens – Parent carer  
Caroline Sawkins - Asperger’s Voice  
Harriet Wilson - Impact Advocacy Supporter for Aspergers Voice  
Nathalie Dick – Carers’ Wellbeing Support Worker for Carers of Autistic Adults (CSWS)  
Julian Morgan – Independent advocate, Autistic UK Director  
Dr Dawn Howard – Clinical Lead Neurodevelopmental Services (SPFT)

### Notes and Actions

#### 1. Update on actions from 22/04/21

Action on page 4 – Katie Glover has fed back the issues raised about mental health services by self advocates and carers to the West Sussex Mental Health and Primary Care Transformation Delivery Group. This included issues around Psychological Therapies and concerns around reasonable adjustment of these for autistic individuals; and Training for staff in all mental health services around

autism including Oliver McGowan mandatory training. The delivery group are keen to maintain a link with the APB and welcome opportunities to involve self advocates and carers in their work when opportunities arise. Louise Patmore is the coproduction lead for the Sussex Mental Health collaborative.

Action on page 5 – there has not been a task group meeting arranged with Time to Talk and this action will need to carry forward. A point of contact in Time to Talk has been passed onto Impact Advocacy for individual concerns.

Action on page 5 – Dawn’s presentation slides were circulated.

Action on page 6 – Dawn will feedback comments from APB at next review. Printing issues were going to be investigated and hard copies circulated to self-advocacy groups.

Action on page 7 – ASSA and Aspergers Voice raised concerns and have not agreed the application. Membership discussed on agenda.

Thanks for long service and valued contributions to the APB’s work was expressed by all to Caroline Sawkins (Aspergers Voice), who has decided to step down.

**Minutes** – the minutes of the meeting held on 22<sup>nd</sup> April 2021 were approved as a correct record and there were no objections to them being published on the WSCC APB webpage.

## **2. APB Terms of Reference review**

This item was to do a health check on the Terms of Reference to see if anything needs updating or adding. It was not about starting with a clean sheet but adding clarity where it is needed. For example, around membership, meeting format and guests and priorities.

### **Membership:**

ASSA member has suggested that self-advocates should be representatives of established self-advocacy groups wholly made up of autistic people. Discussion about what is an established self-advocacy group. Agreed that this currently is ASSA and Aspergers Voice. New and emerging groups can be considered on a case-by-case basis. This consideration will look at if the group is local (significant local presence or branch), members live in West Sussex, and main purpose of the group is to improve the lives of other autistic people living in West Sussex e.g. local issues rather than a regional or national remit.

This change in membership will not be brought in retrospectively so independent advocates on the APB will not be impacted.

The size of membership attending APB meetings has been an important consideration as there is an optimum size for all self-advocates to contribute fully. It was agreed that the APB would not ideally increase Membership further

and new Individuals, groups, or professionals who want to get involved in the work can be invited to subgroups where they have subject matter or lived experience.

Members who have not attended 2 consecutive meetings without giving apologies will be contacted after the 2<sup>nd</sup> missed meeting to check-in and ask if any support required to attend. If no contact after the 3<sup>rd</sup> missed meeting, they will be removed from the membership list and notified.

### **Meeting format:**

Online meetings have been working well. Some Members think they are a better way to work with others missing the human contact.

It was agreed that going forward we will meet online but aim to hold one face to face meeting per year. This meeting maybe a celebration, review, workshop, and December was suggested. It was noted that 'blended meetings' some people online and some in person would be difficult for some self-advocates.

Discussion about invited guests and the issues we have had with presentations, allowing guests to get through their presentations uninterrupted and over running. We discussed support for presenters and how it is important not to undermine the support they can give to the Board's workplan. Allowing the presentation to finish before questions may help with this.

It was agreed to pilot a new approach to see how it works. The Keynote Subject Matter Expert will be asked if they can film their presentation in advance and this will be sent out with the agenda. A 1-page summary will also be provided. At the APB the Expert will attend to do a question-and-answer slot. Members will be asked to evaluate pilot.

Members suggested that Guests make it clear why they are attending e.g., consultation, decision, information only.

### **Priorities:**

The [National Autism Strategy 2021-26](#) was published this week. The APB priorities will link to this Strategy but also cover local issues that fall outside of the strategy.

Members were asked to read through the Strategy and bring to the next meeting ideas for the APB priorities. At the next meeting we will look at short, medium, and longer-term implementation plan and any task groups that need to be set-up to develop this and report into the APB.

Mike reminded the APB that there is a Quality Check available that will help with implementation. A Self advocate suggested Annual Health Checks which has been a consistent ask of the APB. This will be picked up again at next meeting.

### 3. Member Updates and Any Other Business

ASSA update – new members and wider range of meetings including committee, book club, social and ASSA Walks. Discussing returning from lockdown.

Aspergers Voice – transitioning from purely online meetings but no timescales on this as being cautious about number of Covid cases. Looking for a new meeting venue and recruitment a new supporter. One monthly social meeting outside.

Aspergers Voice asked who is taking forward LLS leaflet discussed with Sue Coldham (LLS Operations Manager) that would work with group to coproduce, when Sue talked to group earlier in the year. There has been no further contact.

**Action:** Lisa to ask for an update as Sue Coldham has now retired.

Vaccination update – One self-advocate had found there were lots of changes in the appointment arrangements, venue, which vaccine and appointment time and this led to anxiety. Another self-advocate had to wait a long time because they needed to have a home visit and the Pfizer jab. However, it was a positive outcome as the service was able to make reasonable adjustments, the jab was delivered in their garden by a nurse who understood autism and was able to carry out the procedure without causing distress.

Jayne updated on her involvement with the Institute of Public Policy Research Assembly which is looking at innovative approaches to replan workforce needs. Ends January 2022 and Jayne will update the APB.

Jayne has not heard back from Transforming Care Programme following her involvement in the Expert by Experience group in 2019. Jayne is disappointed that there has been no information shared as it was left in limbo. Lisa said this may need a local approach to be developed.

**Action:** Lisa to find out how Experts by Experience are being involved on the Sussex TCP. Lisa to discuss setting something up locally with commissioning colleagues.

Parent Carer attended the recent Autistica Research Conference and recommended the Mental Health Panel and the interesting research that is taking place. The event has been recorded on [YouTube](#).

Martin updated that My Network, My Network Plus and LIMA services are all very busy. Some face-to-face has continued with My Network Plus on risk assessed basis throughout pandemic but this is slowly increasing. LIMA are looking at what face-to face they will start but no date yet.

Lisa shared link to the [Healthwatch report](#) on Autism Assessments. The APB and self-advocacy groups spoke to Healthwatch earlier this year and there was also an online survey. Lisa shared that the Pathway is being looked at as a

priority/immediately as part of the Sussex NHS LDA Strategy (Kirstie Haines) this is looking at an operating model for Sussex, ADHD and Autism with a single point of access. The long waiting times are across Sussex and this has been escalated to senior levels in both health and social care.

ASSA have been discussing the PREVENT programme and the number of autistic young people being referred because of concerns around their 'special interests'. Self-advocates acknowledge that autistic people can be targeted by people who 'groom them' because of their vulnerabilities but there is a concern that people making and accepting the referrals do not have enough autism awareness and mistake a special interest in for example, chemistry or war as radicalism. Example given of person who was interested in 17<sup>th</sup> Century plague and dressed in costume where the Police arrested as public reported them as 'worrying them'. Suggested that this issue to be considered alongside other priorities at next meeting.

Self-advocate asked about the exemption from isolation for essential health and social care staff and whether they could request their Support Provider, as a reasonable adjustment due to OCD, to only provide staff who had not been 'pinged'. Advised that they should contact the Provider to ask. Link to the [Govt. guidance](#) about when this exemption will apply (strict criteria). Discussed that there should be the principle of giving service users the choice.

#### **4. Agenda items for future meeting**

For the next meeting:

- Action Planning including, priorities to be in 'Implementation Plan', setting up of subgroups, theme of Quality Check.
- LeDeR – this is being changed from a Learning Disability Programme to include reviews of deaths of autistic people. Details locally not finalised but Edel Parson who leads the programme in Sussex has offered to come to September meeting to share plans. Edel's attendance was agreed.

#### **5. Date of next meeting**

2<sup>nd</sup> September 11am – 1pm – this meeting will be online, and a Zoom link will be sent out nearer the time.

Meeting closed at 1pm.