



West Sussex Autism Partnership Board (APB) Minutes

Meeting: Thursday 17th November 2022, 11am – 1pm (online Zoom)

Attendees:

Lisa Loveman (Chair) – Commissioning Manager (WSSC)
Anna Lansley – ASSA; Aspie Trainer
Jayne Simpson – Parent carer
Dan Gregory – Asperger’s Voice
Harriet Wilson - Impact Advocacy
Bodil Scrivens – Parent carer
Rosie Froget - Impact Advocacy Supporter for Aspergers Voice
Vicky Littlejohn – ASSA
Catherine McGill - Co-production Lead West Sussex, Capital Project Trust
Phil Shackell - Interim Deputy Head Mental Health Commissioning Manager (Sussex NHS)
Graham Sargent – ASSA
Joel - ASSA
Martin Ford – Aldingbourne Trust (manager of My Network & LIMA services)
Warren Ball – Autism Specialist (SPFT)
Katie Green - ASSA

Guests:

Diana Bernhardt – Senior Commissioning Manager, WSSC

Apologies:

Mike Smith – Commissioning Officer (WSSC)
Lucy Watson – Carers’ Wellbeing Support Worker for Carers of Autistic Adults (CSWS)
Dr Dawn Howard – Clinical Lead Neurodevelopmental Services (SPFT)
Roxanne Hall – Asperger’s Voice
Maggie - Asperger’s Voice
David Henderson – ASSA

Notes and Actions

1. Welcome and Introductions

Everyone introduced themselves and apologies were recorded.

Praynay has left Sussex NHS and Phil to attend until his replacement in post.

Mark has stepped down after 10 years’ service on APB. The Board wanted a vote of thanks on record for Marks long and important contribution to our work across many areas.

Today is Harriet’s last meeting. The Board thanked her, and everyone said how much she would be missed.

David Henderson has also stepped down from the Board because of new commitment.

2. Update on actions from 22/09/22

Page 2: Anna contacted regarding the Customer and Carers Group.

Page 4: James shared the specification for the collaborative working group. Aspergers Voice will share their feedback by email. First meeting of group held. Vicky has signed-up but couldn't attend first meeting.

Page 5: West Sussex Plan for Autism Week 2023 – not discussed.

Page 7: Dogs for Autism still to confirm which meeting in 2023 they can attend.

No amendments and the minutes of the meeting held on 22nd September 2022 were approved as a correct record and there were no objections to them being published on the WSCC APB webpage.

3. DAM Presentation

Vicky and Graham gave a presentation about a new campaign group that they are part of called DAM which stands for Disabled Autistics Matter. The presentation slides can be [downloaded](#) and cover:

- Who is DAM?
- What DAM mean about 'Disabled by Autism'
- What DAM are campaigning about – their concerns.
- The aims of DAM.
- DAM's action plan.

DAM would like people to join their campaign and there is a new website and [contact form](#) for enquiries. Vicky said that all organisations and groups should look again at how disabled autistic's are represented and pointed out that Parent Carers and advocates can represent people who are unable to represent themselves.

The Chair pointed out that there would be different viewpoints following the presentation which is okay. DAM's presentation today was for information but also for the APB to reflect if there are things we might want to address.

Some autistic members felt excluded by the views expressed by the DAM campaign group as they have lower support needs and/or their disability may be less visible. It was clarified that DAM aims were to raise awareness of the needs of autistic people with higher support needs and find ways to ensure they have a voice. It was made clear that all people needed to be represented.

Some members felt some of the language used in the presentation was divisive and controversial. Graham said that this use of language was intentional and

was being used to get attention. Vicky pointed out that the neurodiversity movement are not considered divisive, even when using strong language.

Two self-advocates raised that they had felt excluded from the LIMA supported Women's Group and there was a need to have groups for disabled autistics as well as those women with low support needs. DAM is saying we need 'all' types of autistic people to be proportionately represented.

Action: Martin to feedback to LIMA

Vicky and Graham thanked for their clear and interesting presentation.

4. SCALE update - Catherine McGill

Catherine is particularly keen for people to contact her with ideas about representing those who struggle with engagement, for example, one person is supporting someone to write down their thoughts and experiences where that is appropriate and relevant.

Catherine wants to get more representation from people that are not accessing services, are not able to participate because of barriers or ignored. Catherine has an Advisory Group which is looking to recruit more members (paid roles).

Contact - Catherine.mcgill@capitalproject.org

Info, and sign up: <https://www.capitalproject.org/introducing-the-scale-network>

5. Annual Health Check – Quality Check Report

Harriet presented the report as Maggie couldn't attend today. The presentation slides can be [downloaded](#). Four Quality Checkers employed by Impact have completed this work. A full report is available as well as a guide and template letter. The Autism Annual Health Checks are not expected to be rolled out until 2024 and there is no update on this.

A meeting has been held with colleagues from NHS Sussex and a number of follow-up actions were agreed:

- Develop a Reasonable Adjustments Directory – Edel Parsons
- Include reference to this work in first LEDER Autism Report due June 2023 – Edel
- Present at the Sussex LDA Board – Anj
- Present at the Sussex Annual Health Check Steering Group – Edel
- Share with APB Leads in East Sussex and Brighton and Hove – Lisa
- Share with Clinical Lead in NHS Sussex (Amy) – Harriet
- Share with AHC Primary care Lead (Penny) – Anj

Phil said that getting this right is important as will benefit all people with vulnerabilities. Self-advocate had an AHC whilst under mental health services

but had not been able to get GP practice to support autism diagnosis, they felt because they did not know about autism.

Action: Phil to find out if GP Practices have a contract to complete AHC for people with serious and enduring mental health.

6. Updates and AOB

Recovery College - Dawn has shared information about the expansion of autism recovery course into West Sussex.

Action: Dawn to bring further information to next APB

Neurodevelopmental Pathway - Sussex-wide work to improve the pathway for all ages in underway. This includes but is not limited to the diagnostic waiting times. Neil will attend next APB to update.

Aspergers Voice – are planning a name change in near future. New name will be Aspective.

Autism and Anxiety Research – Parent Carer updated on the SPFT, and Brighton Medical School research, discuss at previous meetings. ADIE Therapy has been developed and Researchers now seeking funding to be able to provide through NHS. It has been acknowledged that unfortunately the stages from development to delivery take a long time in health services even though there is a gap in targeted therapy.

Reaching Families – Parent Carer shared that Reaching families are recruiting volunteer Befrienders to join and take part in next training course. Sign-up on the Reaching Families [webpage](#).

School of Social Work – University of Chichester currently recruiting people with lived experience to contribute towards the social work degree. Paid role and contact [Fung-Yee Hite](#) if interested.

Direct Payments (DP) – Self-advocate raised that a social care DP can't be used to pay for an health service. They have managed to use it previously for online counselling but have been refused using it to pay for a clinical assessment which is not available on NHS.

Action: Diana to add to MH and Social care task group agenda to discuss how to take forward.

Dates of meetings in 2023:

2nd February

18TH May

20th July

21 September

16th November

7. Date of next meeting: 2nd February 2023 11am – 1pm online.

Meeting closed at 1.15pm.