



West Sussex Autism Partnership Board (APB) Minutes

Meeting: Thursday 2nd September 2021, 11am – 1pm (online Zoom)

Attendees:

Lisa Loveman (Chair) – Commissioner (WSCC)
Anna Lansley – ASSA; Aspie Trainer
Jayne Simpson – Parent carer
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
Warren Ball – Autism Specialist (SPFT)
Pete Ring - ASSA
Bodil Scrivens – Parent carer
Harriet Wilson - Impact Advocacy Supporter for Aspergers Voice

Guests:

Sanjay Mackintosh – Roretti
Louise Hopton-Beatty - Roretti

Apologies:

Joel Benson – ASSA
David Henderson – ASSA
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 22/07/21

Action on page 4 – Lifelong Services co-designed leaflet - Lisa has spoken to Alan Dennett (interim Operations Manager for Lifelong Services). He suggested this work would not begin until the adult strategy had been developed. Harriet has also talked separately to Alan and will now follow this up with him as a different approach was discussed.

Action on page 4 – Transforming Care Engagement of Experts - contact has been made with Fiona Haynes who has taken over from Kirstie Haines. There has not yet been a response so this action will carry forward.

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

Terms of Reference - The revisions to the APB's Terms of Reference were agreed without any further changes.

APB were happy for CSWS to arrange cover whilst Nathalie is absent.

2. APB Priorities and Planning

Presentation:

Lisa introduced this item and our aim to set the APB's priorities for the next 2 years which will support the development of a local action plan.

The APB looked at the priorities in recent strategies and plans:

- National Disability Strategy published in July 2021.
- National Autism Strategy published in July 2021
- Sussex LDA NHS Strategy published in April 2021 – Health focussed.
- West Sussex Lifelong Services vision (Adult social Care)

As well as considering how to improve the lives of autistic people, the APB will need to think about family carers and provision.

It is important to reflect on the areas that the APB have said are important over the last couple of years including:

- Awareness of autism
- Staff training and the roll-out of the Oliver McGowan Mandatory Training
- Diagnosis waiting times
- Homes not Hospital - Transforming Care
- Annual Health Checks
- Suitable housing
- Reasonable adjustments to mental health therapies.

The action planning will have 4 steps as follows:

- I.** Agree priority areas
- II.** Set-up workstreams and overarching aims
- III.** Each workstream to develop an action plan which describes: What we want to achieve? What could work better? and What needs to be done, by whom and by when? This will include wider input from experts by experience etc.
- IV.** APB agrees action plan and receives regular reports on progress.

Discussion on priorities:

Members recommended that the APB focus on 4 or 5 priority areas. The following areas were discussed:

- I. Employment and Volunteering:
 - Continuing work with DWP to ensure the West Sussex Jobcentre network is welcoming and supportive to autistic customers.
 - Increased opportunities for work experience and volunteering including looking at remote/online options.
 - Identify and recognise the specific needs of autistic people during the COVID-19 pandemic.

- II. Understanding autism:
 - Top priority because if this improves all areas of life will be impacted.
 - Significantly improve understanding and acceptance of autism
 - We also want the public to understand how autism can affect people differently.
 - Target public services particularly health and social care organisations.
 - Staff training. Parent carer had a recent experience of a Social Worker who didn't want to listen to the carer as they had worked with autistic people before.
 - Special interests and routines not understood.

- III. Health and Social Care working more closely together:
 - How can we influence organisations to provide more flexible solutions and ways of working?
 - Clear about what the gaps and barriers are from people's experiences of health and social care. Self-advocate spoke about not being able to use accrual in Personal Budget to pay for autism-friendly online counselling whilst they can't access outreach support.
 - Parent carer said that gaps in care appear for young adults who transition from education - linked support to adult social care - unclear what support will be available and delays in getting a needs assessment.
 - Listening more closely and respecting family carers views about their child's specific needs.

- IV. Retention and recruitment of experienced support staff:
 - Building the right support will not be possible if providers are not able to recruit or retain staff. Brexit and Covid has impacted on this and there were already difficulties.
 - Need more consistent staffing and staff with experience and skills.
 - Staff experienced in learning or physical disability but not necessarily appropriate for autism where more creative and flexible support needed.

V. Annual Health Checks

- Included in the Sussex LDA Strategy.
- A quality check could be linked to setting up a service helping to get it right from the outset.

Action: Commissioners to link with health colleagues on this work.

A member suggested that we should align these priority areas wherever possible to the National Autism Strategy 2021 where there may be opportunities to bid for funding.

Transitioning should be covered under each workstream.

Next meeting to agree over-arching aim and setting up workstreams/sub-groups.

3. Adult Social Care Strategy

Sanjay Mackintosh and Louise Hopton-Beatty from Roretti were welcomed to the APB. A filmed presentation was circulated in advance so that this time could be used to answer questions.

Sanjay introduced himself. He has been brought in by the council to support the development of the strategy. He is a consultant who specialises in developing strategies for local authorities and has done this type of work before, mostly in London.

Question – will the strategy cover how health and social care work together? Self-advocate shared story about the inflexibility of using personal budget for something that would help them live a better life.

Sanjay said it was stories like this that they wanted to hear about and build the strategy upon. Improving integration and flexibly delivered services across 2 systems is complex but need to listen to experiences at centre of work going forward.

Question – will autistic people be involved in co-designing the questionnaire. In my experience my daughter really struggles with surveys because of the way questions are structured/written, understanding the intention, not having an option to go outside the box or thinking that there is another answer option not available.

Sanjay – the intention was for the questions to be the same for everyone and an easy read available. The questions will be along the same lines as those in the slides. This will be the same for the structured interviews and workshops. If self-advocates are able and will feedback on the draft survey that would be helpful.

Question- self advocate said she found it difficult to fill in survey's because her special interests will always trump getting started. She would prefer a structured interview. Harriet offered advocacy support if it was wanted within

current resources but if this was being offered widely then additional resources would be needed.

Question – parent carer felt that other carers might feel a bit jaded taking part in another exercise when they are busy and might feel they have provided their stories before, they do not see tangible changes and they don't hear back. What might encourage them to take part this time?

Sanjay – Keith Hinkley is now the permanent Director of Adult Social Care and he has brought in Sanjay and his team to co-design the strategy in this way and provide a framework from which future decisions can be made. We are not starting from a place of services provided and the options for these. Keith is providing the leadership from the top which has not been stable and consistent for quite a while. There is a long road to travel but now is a good time, after the lockdown, to step back and commit to hear what people have said. Including looking at the budgets for different cohorts of customers.

Question – The APB have seen some real success stories since I joined in 2012 but there have been lull's, and this is often when somebody impressive leaves and the great work we have done with them is impacted.

Sanjay – I think committing to this at the top of the organisation will prevent this from happening.

Question – Often it is difficult to see where you/autism fits when strategies are written at a high/aspirational level. How will people's stories be visible in the strategy. Will the positives be drawn out of the co-design so can build on the good things that are happening rather than just the deficits?

Sanjay – we want people with the whole range of support needs to be considered.

Question – Impact would recommend trying to fit in with meetings that are already scheduled rather than trying to set up something separate. Self-advocacy groups are meeting fortnightly, and she will ask if there is space to attend.

Action: Harriet to check self-advocacy groups availability and send dates to Lisa

Question – Is Carers Support West Sussex going to be contacted as they have family carer support groups.

Sanjay – Yes, I have met with the CEO to start this.

Question – Martin asked if the Aldingbourne Trust would have an opportunity to get involved.

Sanjay confirmed they would and shared his email.

Other work that could inform the Strategy included: [Healthwatch report](#) on Autism assessments; Impact reports for My Network+ and Lifelong Services.

Lisa thanked Sanjay and Louise for coming today and asked if they would come back to the APB with an update when the Strategy was agreed.

4. Member Updates and Any Other Business

Aspergers Voice – aiming to recruit new Supporter by end of the month.

Martin updated that LIMA are recruiting an autism specialist. He will share link to advert so Lisa can include the APB to promote it.

Self-advocate suggested that at the end of APB meetings time was available if people wanted to have individual chats in a breakout room with other members or guests. All agreed this was a good idea and will be added onto agenda for next meeting. Impact will help set-up the breakout rooms if required.

Parent Carer updated that their voluntary work with Reaching families was increasingly working with families where teenagers were getting or receiving or struggling with an autism diagnosis. The reputation of the work they are doing is expanding the referrals.

5. Agenda items for future meeting

LeDeR – Edel Parsons will attend December's meeting because of a delay in issuing national guidance.

6. Date of next meeting

7th October 11am – 1pm – this meeting will be online, and a Zoom link will be sent out nearer the time.

Meeting closed at 1pm.