



West Sussex Autism Partnership Board (APB) Minutes

Meeting: Thursday 3rd February 2022, 11am – 1pm (online Zoom)

Attendees:

Lisa Loveman (Chair) – Commissioning Manager (WSCC)
Pranay Chakravorti - Interim Senior Commissioning Manager (West Sussex CCG)
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 – Commissioning Office, Commissioning Team (WSCC)
Roxanne Hall – Asperger’s Voice
Dan Gregory – Asperger’s Voice
Dr Dawn Howard – Clinical Lead Neurodevelopmental Services (SPFT)
Warren Ball – Autism Specialist (SPFT)
David Henderson – ASSA
Harriet Wilson - Impact Advocacy
Mark Bushby – Independent self-advocate

Guest:

Maggie - Asperger’s Voice

Apologies:

Bodil Scrivens – Parent carer
Rosie Froget - Impact Advocacy Supporter for Aspergers Voice
Joel Benson – ASSA
Nathalie Dick – Carers’ Wellbeing Support Worker for Carers of Autistic Adults (CSWS)
Pete Ring – ASSA

Notes and Actions

1. New Members

Pranay was welcomed as the interim senior commissioner for mental health from West Sussex CCG. Pranay covers community mental health and autism.

APB agreed invite to Suzana Sheppard (Mental Health and Autism Coordinator) from Carers Support West Sussex to join the APB. Due to a restructure Suzana will replace Nathalie Dick.

2. Update on actions from 02/12/21

Action on page 2 – Email from APB to Strategic Lead LDA (Learning Disability and Autism) Sussex CCG Commissioners – Fiona Haynes, was agreed. Fiona

suggested, as there are no current vacancies on the LDA Shadow Board and a review of membership only happened at certain intervals, West Sussex APB could submit an expression of interest to join ready for next recruitment phase. In the meantime, Fiona suggested that if themes related to the LDA Boards programme of work came up at the APB then we were to forward minutes to her team. We do not know who attends the shadow board from West Sussex.

Action: Diana Bernhardt (Senior Commissioning Manager, WSCC) will follow up when she attends the next LDA Board. She will ask for: Terms of Reference; who is current West Sussex rep.; and how carers voice is feeding through. Dawn offered to raise with her Head of Service (SPFT) who also attends.

Action: APB to select a self-advocate and carer to be put forward for next recruitment round. Expressions of interest needed.

Action on page 4 – Edel is being booked to attend an ASSA meeting. Dawn will share Scandinavian research with Edel.

Action on page 4 – Bodil found out about the Swedish autism health offer from a contact who has lived experience. It's not an entitlement to an annual check, but to whatever support you need to put you on an equal basis with others in society. The underpinning law covers autism, learning disabilities and physical disabilities, and the costs of the services are picked up by whatever local or regional council or health trust that applies, depending on the type of support that is needed. Services must be of 'good quality', co-ordinated and long-term. The individual support plan must be reviewed at least once a year with the involvement of the person concerned. There are certain details and limitations based on age of diagnosis and condition not being due to the 'normal ageing process' etc. In the case of her contact in Sweden they receive speaking therapy (monthly or weekly) and a personal assistant to help with meetings, appointments and contact with authorities etc as and when it's needed. The psychologist who provides the therapy specialises in autism/neurodiversity, but the personal assistant has not been specially trained although is very competent, patient, and tenacious.

APB to consider good practice models from other areas to feed into Workplan Priority 5.

Action on page 4 about Adults Social Care Strategy and Page 5 NDT update covered on today's agenda.

Action on page 5 – David has shared information on SPFT research into anxiety and autism title 'Interoceptive training to target anxiety in autistic adults (ADIE): A single-centre, superiority randomised controlled trial'. Lisa to share this with LEDER lead.

Action on page 5 – [Link](#) to Oliver McGowan mandatory Training Stakeholder event shared.

Minutes – the minutes of the meeting held on 2nd December 2021 were approved as a correct record and there were no objections to them being published on the WSCC APB webpage.

3. 2022 Quality Check

A briefing paper detailing this year's quality check was shared with APB to agree. A draft project plan, which will be reviewed and finalised once the quality checkers are appointed, has been prepared by Impact. Funding has been provided so Quality Checkers can be employed and Impact will start recruiting to 4 roles in February (10 hours paid work on offer). The quality check work will start in March with an aim to report back to APB in September 2022. To ensure this work will inform any future introduction of Annual Health Checks for autistic people we will need to involve those people leading on this in the CCG. A task group will be established.

Member asked how the voice of parent carers will be included in this work. This was discussed and everyone agreed this was important. Where someone has a carer then they were often the eyes and ears for the autistic person. It was agreed that parent carer(s) will sit on task group including Suzana from CSWS if available. The task group may decide to carry out some parallel work with carers to compliment the quality check with autistic adults.

Member asked what would the guide look like, was it for GP Practices or families? The guide would be for autistic people and would be sent out with invitation to attend with aim to encourage take-up.

The Board agreed the Quality Check brief.

Action: Lisa to set-up AHC task group meetings.

4. Strategy for Adult Social Care

Strategy endorsed by Cabinet Board on 1st February [webcast](#). A copy of the Strategy is available [here](#) including an easy read version.

Background - since September 2021, the council have been co-designing a longer-term vision for adult social care, based on how staff, customers, carers, and partners have described what a good life looks like to people with care needs and their carers. This included:

- Held workshops with staff and organisations that provide care across the main cohorts of people that have care needs.
- Held focus groups with customers and carers to better understand what a good life looks like to them, and have their voices heard.
- Ran a survey for staff and people who live in West Sussex, to which over 1,000 responses have been received.
- Connected work that has already been completed or is underway, to which this strategy will act as a guide (e.g. the dementia strategy, carers strategy) and set up a Sounding Board to guide the work from the outside in.

The APB and self-advocacy groups contributed to this work.

Keith Hinkley, the Director of Adult Social Services (DASS) said that the strategy is:

- An articulation of the voices of people who access care and carers in the main care groups that WSCC provides or commissions care for.
- A document that puts people who access services at the centre of planning priorities and the things will be delivered in the future, so it is structured by what people have said is important to them vs structured (for example) by cohort group.
- A document that shows intent for what will be done to meet the expectations that customers and carers have for leading their best life. This may include the role partners might play.

Next step - strategy delivery work will now begin and include remodelling directly services through co-production.

Member asked if feedback can still be given as they wanted more acknowledgement that some people do not have carers or family and friends and did not have a support network to draw-down from. Lisa said that because the future remodelling and planning was going to be coproduced there would be opportunities to continue to input.

5. Update from SPFT Neurodevelopmental Service

Dawn shared presentation. Current commissioned is 2.3 whole time clinicians who make up the West Sussex autism diagnostic assessment team. Small resource who they estimate get 5 times more work than capacity.

Consequently, waiting times have grown. SPFT decided to no longer describe length of the waiting list as this was confusing as each referral is triaged against risk or if transitioning from CAMHS waiting list and it would be different for individuals. This is explained in referral acknowledgment letters.

West Sussex has access to a Peer Support Specialist who has been working on a 1-year pilot for 2 days a week offering between 3-6 post diagnosis support sessions. This has received very good feedback from recipients and SPFT are hoping that more autism hours will be commissioned. APB Member had personal experience through the mental health peer support and found this to be very helpful.

TCAT (Transforming Care Autism Team) which is Sussex wide 14+ continues to be in great demand however they have a very narrow eligibility criteria only accepting people on TCP Register. Member asked if TCAT reviewed the medium- or longer-term outcomes of those people they had supported i.e. did they avoid hospital admission. This has not yet been done and the focus has been on the outcomes at discharge from TCAT.

Referrals have increased because of: increased awareness of autism; positive impact of diagnosis; increased complexity of inpatient referrals meaning that

each assessment is taking longer to complete; and the referral pressures on CAMHS which mean higher number of young people transitioning to adults still waiting for an assessment.

No news of new investment however ongoing meetings with the Integrated care system (ICS) for Sussex. Capacity and waiting-times an all-age, Sussex-wide issue. A Sussex-wide 'Neurodevelopmental Conditions Target Operating Model' has been developed, led by a health consultant Kirstie Haines, workshops held in autumn 2021. Awaiting commissioning intentions from this and details of outsourcing to a private provider being considered to clear back log. In meantime SPFT have begun some unfunded recruitment to increase administrator time and employ a Triage/Duty worker to maximise specialist practitioner time.

There is a shortage of specialist trained clinicians to complete assessments so SPFT want to build this into structure - looking at duty workers being training posts, building diagnostic capacity in other parts of SPFT, establishing a Training Academy; expanding Mind District (an IT Platform for sharing self-help guides and joining support groups) which could be used to develop post diagnostic offer e.g. sharing TCAT OT's Care Support Plans and expanding the Peer Support Roles.

Member asked about pre-diagnosis signposting to support. SPFT have this on website [here](#). Member said that given the waiting times it was even more important that voluntary and community sector partners were included as part of the whole offer as each can play a part in support to strengthen the networks. Dawn explained that part of Peer Support Role is to keep the signposting information up to date.

Member asked about assessing for other conditions such as Dyspraxia, ADHD, Dysmorphia which are more common amongst autistic people and are only diagnosed in NHS for children. This is currently a gap in provision with the service only able to provide advisory information to GP's if this is picked up at autism assessment. Workplan Priority 3 includes 'Co-morbid diagnosis – develop clear integrated dual diagnosis and post diagnosis pathways', this work is yet to start.

Action: Lisa to share presentation slides with minutes.

6. Task & Finish Group – Employment & Volunteering

Mike updated on establishment of this group starting 17th February. Members include the Supported Employment Service, DWP, Roxanne, Mark and Bodil from APB. Timing good as new national framework piloted across 15 Job Centres ends in March which can help inform work. Important to get some baseline information so please pass on experiences to Mike. Mike to review APB minutes when looked at this previously with DWP attending meeting. Mark has worked with DWP and pictorial guides to visiting Job Centres developed. David

is speaking with his previous employer and can ask questions about diversity and hidden disability.

Members commented that they had had a better recent compared to past experience and felt improvements had been made. One member said her recent diagnosis had made all the difference because she now felt she had permission to ask for reasonable adjustments which included being interviewed in a quite private space. ASSA recently responded to Government Green Paper.

Action: Andy to ask ASSA if the Green Paper response can be shared with Task Group.

7. Member Updates and Any Other Business

ASSA meetings to now begin face to face in February.

Understanding Autism Event will resume in May 2022. More details to follow. Member asked if it can cater for people who want to access remotely.

Martin reported that the Ask LIMA training sessions for Aldingbourne staff are being well received. He will check if these can be opened to outside organisations.

Jane has completed the Maudsley Train the Trainers course and is now waiting to be matched with NHS Trusts. Jane has also joined SPFT 'Working Together Group', a forum for Experts by Experience.

8. Date of next meeting: 31st March 11am – 1pm.

Meeting closed at 1pm.