



# Autism Partnership Board

## Minutes

**Meeting:** Thursday 22nd April 2021, 11am – 12.30pm (online Zoom)

### **Attendees:**

Lisa Loveman (Chair) – Commissioner (WSCC)  
Nathalie Dick – Carers' Wellbeing Support Worker for Carers of Autistic Adults (CSWS)  
Anna Lansley – ASSA; Aspie Trainer  
Jayne Simpson – Parent carer  
Harriet Wilson - 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  
David Henderson – ASSA  
Bodil Scrivens – Parent carer  
Caroline Sawkins - Asperger's Voice  
Dan Gregory – Asperger's Voice  
Julian Morgan – Independent advocate, Autistic UK Director  
Dr Dawn Howard – Clinical Lead Neurodevelopmental Services (SPFT)

### **Guests:**

Katie Glover (CEO, West Sussex MIND)  
Bikram Raychaudhuri (GP and Clinical Lead Dementia and Mental Health West Sussex NHS CCG)  
Laura Ferguson (Lead Psychological Wellbeing Practitioner in Primary Care - Time to Talk Coastal)  
Jess Dare (NHS psychological therapist Time to Talk Coastal)

### **Apologies:**

Mark Bushby – Independent advocate  
Warren Ball – Autism Specialist (SPFT)  
Joel Benson – ASSA  
Graham Sargent – ASSA  
Pete Ring - ASSA

## **Notes and Actions**

### **1. Update on actions from 04/02/21**

(i) What the approach will be by vaccination teams to reasonable adjustment requests (Lisa Loveman):

- Information was shared that there are 'Quiet Sessions' and home visits which can be requested at time of booking.
  - CCG have passed on that if you are eligible for vaccination but haven't had first dose you can email: [sxccg.vaccineenquiries@nhs.net](mailto:sxccg.vaccineenquiries@nhs.net), put in subject line: Haven't had first dose, and include following details: Name, Address, DOB, NHS No: if known, GP Practice, Contact telephone No, Reason for not having first dose: Housebound, Autism and OCD which causes severe functional impairment; Reasonable adjustments requested: Home visit. Vaccination in garden.
  - Self advocate was confused why they had not been called up yet by GP Practice. Impact offered support to anyone needing help to follow this up.
- (ii) Check with each District and Borough Housing Dept how autism is captured on housing application (Mark Dow).
- (iii) WSCC Housing Lead take forward feedback and the findings from the APB quality Check and Carers Consultation (Mark Dow).
- Actions (ii) and (iii) to carry forward as 'the housing world is focusing on the dramatic rise in homelessness now as lockdown eases'.
- (iv) Find out if Housing Officers have been trained (ASPIE Trainers).
- ASPIE trainers are very busy but will follow-up with Housing Teams. Asked if there is help available to create contacts/openings. [Mark Dow](#) would be best placed to assist with contacts of housing dept. leads.
  - Independent advocate is advancing issues for autistic people to Housing providers through his membership of the SET-UP forum and work with Brighton & Hove and Worthing Councils.

**Minutes** – the minutes of the meeting held on 4<sup>th</sup> February 2021 were approved as a correct record and there were no objections to them being published on the WSCC APB webpage.

## **2. Mental Health Discussion**

2 questions were covered in the meeting and 2 questions to carry over to next meeting.

*Question 1: 'As we know high levels of anxiety can be very common for people with autism, something that has been undoubtedly exacerbated by all the changes and difficulties brought about by the pandemic. Standard therapies aren't always appropriate for those with autism, are there any new approaches being considered or incorporated into local services currently?'*

It was stated that Time to Talk is a commissioned service. This means that what is delivered, and the type of mental health conditions covered by the service is within strict criteria. Time to Talk also adhere to NICE guidelines for therapies. Autistic people and those with ADHD are not excluded and there is NHS guidance that its services must make reasonable adjustments for LD and

Autism. The Time to Talk service is open to ideas on how they can do this better and would like input from different groups.

In hearing about Time to Talk's approach Members fed back that there had been a mixed experience – a positive experience with counselling but also difficulties getting the help needed. Autistic adults pointed to the following issues:

- Difficulties completing questionnaires which determined if service was given or not.
- Long waiting times
- An offer of CBT and no alternative
- Difficulties meeting eligibility for counselling
- Difficulties in setting Goals
- Time limits on interventions

It was stated that a GP would look at the person holistically and if there was a high level of anxiety acknowledge this and look to help. This would include looking at what is going on around the person and any support they had available to them. A referral to Pathfinder is a way that some support can be provided locally and whilst waiting for treatment and may prevent anxiety from getting worse.

Members said there was not enough understanding of how mental health and autism are interlinked and therefore lifelong. A mental health condition can be made more manageable with therapy and this can lead to better quality of life.

Members agreed that the key issue was that there was no specialist autism service for mental health. CBT requires adaptation to meet needs of autistic person and training for all NHS staff in autism is key. The Oliver McGowan Mandatory Training will cover Mental Health practitioners and this should help in the absence of a specialist service.

It was discussed that autism leads to anxiety with release of adrenalin and that can be exacerbated by 'talking to people'. Autistic people often find they are 'shifted on' or labelled 'too difficult' to carry-on working with because of this.

The difficulties reported were acknowledged by all. It was stated that Time to talk staff had received training in neurodiversity including autism and Aspergers and it was a requirement to consider the adjustments needed.

Members stated that it is currently potluck if you get someone who really understands autism and that is not right, and autism awareness should be embedded across the system. Sometimes you spend longer telling the practitioner about autism than discussing the things you came to counselling for.

These difficulties impact family carers, whilst the autistic person is not getting the help they need the carer is having to cope with a deteriorating family

member. Long delays in autism diagnosis also impacts. It was stated that is important to remember the triangle of care and that carers are not left out of the treatment plan and decision-making.

It was stated that positive outcomes are achieved when SPFT have been able to provide extended post diagnostic support following autism diagnosis. Sussex Partnership Foundation Trust (SPFT) are developing the following:

- Training films by people with living experience.
- CAG (Clinical Academic Group) which is building evidence-based practice, including incorporating the latest research into therapies. Unfortunately, usually a long lead in time.
- Digital Platform to access coproduced materials being developed in Brighton.
- Wellness Recovery Action Plan (WRAP)
- Longer-term vision for a Training Academy
- Establishing trust to share issues – Practitioners awareness that this can take longer.

It was agreed that going back over quite a long time these issues have been discussed and it would be good to feel that there could be some progression around more systemic reasonable adjustment in Time To Talk and specialist SPFT therapies. It was felt it needs Commissioner and Provider involvement to move this and it was recommended that it is fed into Community Transformation Programme. This current climate, the NHS Long Term Plan and new mental health investment should help move things forward. There is a proposal for a new Neurodevelopmental Pathway and to address the Health Inequalities faced by particular groups including autism. It was agreed that this had been a timely discussion and a reminder why every segment needs to be looked at.

**Action:** Commissioning issues to be fed into Community Transformation Programme (Bikram and Katie).

It was noted that Brighton & Sussex Medical School are advanced in a research study into an anxiety reduction therapy, working with the Sussex Partnership NHS Trust, based on increasing self-awareness about heart rate. It was not clear when NICE decisions about this therapy will be made.

It was stated that Pathfinder services are run by different organisations in different areas of West Sussex and each works in a slightly different way and offers slightly different things. Katie will respond if there are issues with the ones run by West Sussex Mind who said that many Pathfinder services have also had autism training.

It was raised that in 2019 the APB held meetings between Time to Talk and self-advocate reps. Several issues were identified around the referral process and the questionnaires that people were asked to complete ahead of their first

session. It was found at the time that Time to Talk were not able to unilaterally alter any of the questionnaire. The last meeting was due to take place in Feb 2020 but was cancelled because of Covid so needs to be set-up again.

**Action:** reschedule meeting with self-advocate reps and Time to Talk (Mike).

Question 2: *'Autism and vaccination. Since people on the LD register were put on the priority list (including very mild LD), it feels strange that autism is not included. While autism is not an LD, the issues faced in terms of health inequality can be similar. Therefore, why is there not an autism register? Autistics, too, could benefit from regular health checks and the flu jab etc.'*

It was stated that the decisions about who is in the priority group is made at the national level by the Vaccination Board (JCVI) and not in Sussex. The priorities were set against 'risk to life'.

A self-advocate said the decision to include mild learning disability and not autism with complex needs didn't make sense.

It was noted that Annual Physical Health Checks (GP Autism Register) are in the Sussex LDA and NHS Long Term plan. A self-advocate suggested that although the national Covid emergency determined the priority need for at-risk categories, it's local patient medical records which hold the data, so a local West Sussex register is as possible for autistic people as it is for those with learning disabilities.

SPFT stated they are putting a proposal together in the Neurodevelopmental service to gather research figures as part of the diagnostic clinic on the specific physical health needs seen in neurodivergent people - especially joint hypermobility.

It was noted that nationally the NHSE Autism Team have decided to ask Autistica to recommend what autistic people need.

### **3. Sussex Police Autism Passports**

Dr Dawn Howard (SPFT) presented information on the development of the Sussex Police Passport. This also included work to improve custody suites.

**Action:** Copies of the presentation slides to be circulated to the APB (Dawn)

The Passport had been launched during world autism week. It was noted that the Passport had also been presented to the Sussex CCG LDA Board where an offer of some help had been made available to promote it more widely and to develop an APP to work on mobile phones so will not have to rely on paper.

It was reported that there is an issue with printing Pdf as page 2 and 3 area reduced size.

Emergency chat App – Members felt this wouldn't work for everyone in a crisis or if someone has selective mutism. Could other options be listed for example,

an App with speech assistance? It was acknowledged that it would work for some people and not for others.

Members asked if the QR code that links to Pegasus card could be added to the Autism Card as well.

There was a concern raised about 'safeguarding' as so much personal information was on the card and whether it could open someone up to being bullied.

**Action:** Raise comments or feedback for any future revisions to the card  
(Dawn)

#### **4. Member Updates and Any Other Business**

Oliver McGowan Mandatory Training – It would be good to find out what West Sussex Organisations are planning to add this to their strategies. To discuss how best to do this at next APB.

A request has been made to join APB. It was agreed that self advocates would have more time to consider request and to let Chair know if any objections by email by 6<sup>th</sup> May.

**Action:** Consider request for Membership of APB (self advocates)

Future meetings were discussed as it becomes possible to have face to face meetings again. There was concerns that this would be difficult for some members and plenty of notice is required. It was suggested that going forward a mixture of online and face to face could work better.

#### **5. Agenda for next meeting**

Continue with the Mental Health discussion. APB members would like to hear what the Mental Health transformation programme is about, how it covers Autism, the intended timescales, who is involved, and how the APB, self-advocates and others on the spectrum can get involved.

Today's Guest Speakers to be invited back.

#### **6. Date of next meeting**

22<sup>nd</sup> July 11am – 12.30pm – this meeting will be online, and a Zoom link will be sent out nearer the time.

Meeting closed at 1pm.