



## West Sussex Autism Partnership Board (APB) Minutes

**Meeting:** Thursday 18<sup>th</sup> May 2023, 11am – 1pm (online Zoom)

### **Attendees:**

Mike Smith – Commissioning Lead (WSCC) – Chair  
Lisa Loveman – Commissioning Manager (WSCC) - Minutes  
Anna Lansley – ASSA; Aspie Trainer  
Jayne Simpson – Parent carer  
Dan Gregory – Asperger’s Voice  
Maggie - Asperger’s Voice  
Sophie Storer - Impact Advocacy Supporter  
Chelsea Harwell – ASSA Supporter  
Bodil Scrivens – Parent carer  
Sheryl Bunting – Learning Disability and Autism Lead (CSWS)  
Olesya Buck – Mental Health Commissioning Sussex NHS  
Lesley Durbin – Impact Advocacy Manager  
Katie Green – ASSA  
Graham Sargent – ASSA  
Warren Ball – Autism Specialist (SPFT)  
Martin Ford – Aldingbourne Trust (manager of My Network & LIMA services)  
Rosie Froget – Aspergers Voice Supporter

### **Guests:**

Hilary Armour – CEO Dogs for Autism

### **Apologies:**

Diana Bernhardt – Senior Commissioning Manager (WSCC)  
Dr Dawn Howard – Clinical Lead Neurodevelopmental Services (SPFT)  
Catherine McGill - Co-production Lead West Sussex, Capital Project Trust  
Roxanne Hall - Asperger’s Voice

## **Notes and Actions**

### **1. Welcome and Introductions**

Everyone introduced themselves and apologies were recorded.

Olesya Buck will be attending from mental health commissioning team in ICB reports to Diane Bardwell.

### **2. Update on actions from 02/02/22**

LIMA Women’s Group – self advocate asked if LIMA could switch from using TEAMS to ZOOM for online meetings which they believe is more widely available to autistic adults. Martin will take this request forward and also confirmed that

people can join the Women's Group once they have met with the coordinators to agree that it will meet what they need. New Joiners all start together on a quarterly basis rather than ad hoc. Self-advocate reported that because she advocates that autism is a disorder/disability she 'felt gaslighted' by the Group and has now left. Martin happy to hear any individual concerns directly.

Aspergers Voice is going to rename group 'Aspective' - no date yet for switchover.

Employment - **Action** to invite Tim Claydon from DWP to give an update (Mike).

Neurodevelopmental Pathway Programme – Neil Johnson asked for case studies to support this ongoing work. Self-advocates are finalising these and Sophie will forward. Slides have been shared but flyer has not been received. Parent Carer asked for an update on the workshops with people with lived experience and how they will be involved in the Programme. **Action:** Find out status of Workshops (Mike)

### **3. Presentation from Dogs for Autism**

#### Slides

Welcomed Hilary who is the CEO at [Dogs for Autism](#). Hilary showed a film about the charity and then talked through her slides.

Hilary told us that dogs are matched with people of any age and there is no cost to the individual. Each dog costs £25k to train and during its lifetime. The dogs are highly trained, and Dogs for Autism are members of Assistant Dogs UK (national charity). Research is underway on the impact of having a dog, but benefits include companionship, calming, help with emotional dysregulation, removing people from risky situations, interrupting behaviours, depress therapy, provide safety tasks such as road safety, creating space in crowd, help with routines including medication, teeth cleaning, bedtime, fetching things, being a social conduit. Overall they help increase someone's independence by increasing their confidence. Dogs are trained in a bespoke way according to the needs of the human partner.

The dogs are different from therapy Dogs which do not live with you.

The charity relies on funding to supply and increase the number of matched dogs. Dogs are in high demand and there is a long waiting list/time. Commissioners could fund a number of dogs and this funding would be ringfenced for people in area, but it could not be ringfenced for a specific individual.

Self-advocate asked what would happen if autistic advocate lived on own and didn't have any support paid or family to help care for a dog. Hilary said at present the charity requires there to be a back-up/third party if you are unable to care for the dog. Hilary agreed that looking ahead the charity could look at ways of linking a person on their own with local support networks.

Self-advocate said they had developed a dog phobia but would love to recover from this and get a support dog. Currently the charity does not help with this, Hilary recommended Pets as Therapy who have dogs that you can have access in time limited way and a gradual programme and are trained to be quiet and gentle.

Self-advocate asked how legally these dogs are viewed? Hilary advised that legally assistance dogs are the same as Guide Dogs as long as highly trained and no public health hazard. With exception of air transport, their use is protected by law and under a reasonable adjustment 'Equalities Act'. Awareness of the law is sometimes lacking.

Parent Carer reiterated that for autistic adults they will often live independent of family or support workers and developing links with alternative support in community would be helpful going forward.

Self-advocate asked if Pets for Therapy could be invited to a meeting. Sophie will take this forward with ASSA and Aspergers Voice group meetings.

#### **4. SPFT update on the Neurodevelopmental Service**

Warren updated on the neurodevelopmental service in West Sussex. The waiting times for a diagnostic assessment is at its highest length. The service is severely limited in what can be done about this and ICB Commissioners are fully aware. This has also been on SPFT risk register for several years and the Trust have invested some contingency funding to help reduce risks and increase admin and autism training across the Trust. Compounded by waiting list in CAMHS and children not receiving a diagnosis before 18th birthday so transfer to adults waiting list. Service receives 80-100 referrals per week and higher following coverage in press or TV. 11,000 people waiting across Sussex. Service is only able to see most unwell people who are usually already in hospital. ADHD is not included in West Sussex service despite the team seeing many people with both conditions.

A third of the team are neurodivergent themselves or have a caring responsibility. SPFT have a neurodivergent staff clinic and staff network. Jess Eccles (SPFT) is running a Brain and Body Clinic which links the physical health conditions associated with autism such as hypermobility and vitamin deficiency.

SPFT have engaged Peer Support workers to work with people pre and post diagnosis. This has been successful but unfortunately a waiting list has also developed.

The team consult with and support other services and in particular the Early Intervention and Psychosis services where people have been misdiagnosed. Self-advocate asked if the language used by the service could be reviewed and rather than neurodiversity use disorder and disability. Warren will look at this with his team.

Discussion took place about recent Panorama programme which uncovered poor standards and wrong assessments in private diagnosis of ADHD. Warren said that their contract allows for 12 hours per assessment which includes on average 4-5 hours direct contact. Each assessment is reviewed by the MDT and most have 2 clinicians involved.

The APB have expressed concern about the waiting list and times in past and wanted to know what they could do today. Sheryl said this was the most common issue brought to CSWS from family carers and it caused stressed and prevented people accessing support and benefits. It was suggested that this remains on the APB regular agenda as it is a high priority area. It was suggested that Neil Johnson, who came to the last APB and is leading on the NDP Programme, be asked back to the APB to explain what the delay is in implementing a new Delivery Model for Sussex.

**Action:** Everyone who has a case study to share with Neil Johnson (as requested at last APB).

## **5. Updates and future agenda items:**

Autism Training – aim to reschedule this item for next meeting.

Parent Carer updated that had co-facilitated a workshop at the Adult Social Care Staff Conference and she was pleased to see that service users have been involved in WSCC staff recruitment processes. She also co-facilitates a carers training course for complex emotional needs and personality disorders which aims to give carers coping strategies in dealing with difficult situations and information about diagnoses etc. Carers have reported this training is very helpful. Carer suggested that Warren's Team might want to look at this model as 10-15 carers on each course over Zoom is low cost.

Parent Carer updated that Reaching Families have just expanded number of volunteer befrienders so can support more referrals from families of people of any age. Carers adult daughter has just benefited from some good work experience supported by 'Y-Wish' but support only available 18-24-year-olds.

ASSA have been following up with the government about their plans to get more autistic people into employment. The target is 30% more people in work. ASSA are concerned about the positive stereotyping of autistic people around what good employees they make e.g. messaging such as - never off sick, can work under pressure, great at spotting patterns and dealing with repetitive tasks. ASSA are concerned that they lump all autistic people together under these stereotypes and that no one is challenging this.

APB agreed that Tom Elsam – Service Manager in Lifelong Services can join the APB at next meeting to represent operational social care.

## **Dates of next meeting:**

20<sup>th</sup> July 2023 @ 11am online