



## West Sussex Autism Partnership Board (APB) Minutes

**Meeting:** Thursday 31<sup>st</sup> March 2022, 11am – 12.30pm (online Zoom)

### **Attendees:**

Lisa Loveman (Chair) – Commissioning Manager (WSSCC)  
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 Officer (WSSCC)  
Roxanne Hall – Asperger’s Voice  
Dan Gregory – Asperger’s Voice  
Warren Ball – Autism Specialist (SPFT)  
Harriet Wilson - Impact Advocacy  
Mark Bushby – Independent self-advocate  
Maggie - Asperger’s Voice  
Bodil Scrivens – Parent carer  
Rosie Froget - Impact Advocacy Supporter for Aspergers Voice  
Katie Green – Asperger’s Voice  
Graham Sargent - ASSA

### **Apologies:**

David Henderson – ASSA  
Suzana Sheppard – Carers’ Wellbeing Support Worker for Carers of Autistic Adults (CSWS)  
Dr Dawn Howard – Clinical Lead Neurodevelopmental Services (SPFT)  
Pranay Chakravorti - Interim Senior Commissioning Manager (West Sussex CCG)

## **Notes and Actions**

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

Today’s agenda has been shortened and the Carers item will be covered at next meeting.

### **2. Update on actions from 03/02/22**

Action on page 2 – Lisa to find out more details about the LDA Shadow Board including what method they use to meet (Zoom, Teams or in person), frequency of meetings and if regular time level of commitment and day ahead of asking people to volunteer.

Action on page 4 – Annual Health Check task group has not yet been set up. Information from NHS is that Autism Annual Health Checks are 1-2 years off

being rolled out and they haven't yet got to a pilot stage. Sussex will be applying to run a pilot and if this goes ahead then this will be the time to set-up a task group. The Quality Check will continue, and Harriet has liaised with the Sussex NHS leads about this work. They have given a steer on the questions to ask and are keen to take forward any learning in the primary care action plan. Newcastle University are developing an Autism Health Check template and Harriet will be looking at this.

Action from Page 8 – ASSA will discuss sharing Green Paper feedback with employment task group at next week's committee meeting.

**Minutes** – the minutes of the meeting held on 3<sup>rd</sup> February 2022 were approved as a correct record and there were no objections to them being published on the WSCC APB webpage.

### **3. Members updates**

Member updated on her involvement in the SPFT Lived Experience Project. She was on the OCD group and has been able to share experiences of autism and OCD. The groups have Professionals and People with Lived Experience working together on research proposals. There are payments made for contributing.

Member updated on the [Reaching Families](#) offer. She has been involved in training 9 new Befrienders as well as supporting a family matched with her. All the families have a child or young person who has recently been diagnosed with any condition and the support is helping them guide through the maze and stand alongside them as they do this. The 'Making Sense of it All' booklet lists services and activities for adults and children.

Member updated that planning for the Understanding Autism Event on 6<sup>th</sup> May is well underway and there are still spaces to book. The programme includes Camouflaging, ASD and Memory, Reasonable Adjustments in workplace and ASD and Identity. A copy of the programme to be shared with minutes to promote. <https://www.eventbrite.co.uk/e/understanding-autism-2022-tickets-242748847337?aff=ebdssbdestsearch>

Action: Please can you re-promoted in your networks

Member asked for an update on Autism Diagnosis as they want to provide accurate information to people, they are in contact with. Warren said the service was in business continuity measures because of the waiting times. The service is not able to let people know how long they will wait and is only doing commissioned work. West Sussex has a small WTE 2.6 team and have carried 25% staffing vacancy which they have not been able to recruit a Speech and Language Therapist to. All referrals are triaged, and RAG rated. Greens are waiting minimum of 3 years and Red's can be up to a year. Reds are likely to be in hospital and Ambers known to secondary mental health. Member asked if GPs know about this backlog and are offering people the '[Right to Choose](#)' and can refer people elsewhere. Discussed there is a nationwide issue with shortage

of professionals to assess. Sussex NHS will be procuring a service to help tackle the waiting lists.

Member has made a complaint via PALS about the lack of autism specialist health support once someone is in the community. TCAT had provided expertise and recommendations for a bespoke care package which enabled a hospital discharge. Now the person is in the community there is a risk of readmission because of lack of understanding of autism and no Lead Practitioner. Member will feedback outcome of complaint.

Member updated on a charity she is involved in called [Dogs for Autism](#) that was established in 2018. The dogs can support with independent living and emotional support. There are 2 routes 1) Fully trained dog can take up to 3-years and costs covered by charity. 2) If you have a dog that can be trained there is 'Paws-able' where over 18-2 years together with owner the dog is trained.

3 self-advocate members recently attended the National Autistic Society annual conference on mental health. Places were sponsored and there was a view that this was expensive at £78 per place. One member felt that she hadn't learnt anything new and was disappointed that issues being raised had not progressed.

Member has made a complaint via SPFT and PALS regarding following trust guidelines which say that if autistic person is prescribed anti-depressant medication, then they should receive regular monitoring. Since making the complaint the public facing guidance has been removed. The member has not heard back about the complaint. Impact offered support with following this up. Member will check why guidance has been removed and if this needs to be escalated will report back.

#### **4. Staff stories discussion**

Lisa introduced the discussion using some presentation slides. The aim of this work area was to support the recruitment and retention of experienced support staff. The APB want to ensure that health and social care workforce feel valued by autistic people and their families. Important to build up rather than knock down so celebrating the important role support staff can play in someone's quality of life, enabling someone to live as independently as possible and supporting family carers. What we said we needed was a collection of stories that illustrate and promote the importance of support staff role that can be used in recruitment campaigns.

Who can we ask? some self-advocates have support staff, impact advocacy and LIMA have people who have support staff, and family carers. It would be good if we can offer to pay people for their time.

Need to include friends as well as families and highlight how having consistent staffing can impact peoples lives

Key ingredients? Supporter can meet individual needs. People need staff with a range of experience and age. There is a tendency to recruit young people, but they do not always have life experience needed to run household, access community services and push for mental health support. Some 'Talking Head' video or audio clips would be good for social media posts. Where there isn't a perceived career path staff turnover is a problem. Issue with building trust, which takes time, and then having to start over again.

**Action:** Lisa to engage with the Proud to Care team at WSCC about how to take this forward and draft a briefing based on today's discussion.

### **5. Any Other Business**

The planned Autism awareness Event in 2020 didn't go ahead because of Covid. Members think we should continue to look at this as part of the Workplan priority 2: Understanding Autism. Suggested we aim for Autism awareness week 2023. It was suggested that people's stories could be recorded and shared virtually. To add to next meeting for further discussion.

Employment Task Group has been meeting and a plan is evolving on how to improve people's experiences of using the job centres. This includes being early adopters of the DWP autism accreditation scheme and making environmental changes, staff training, quiet or adjusted sessions, autism passport. Also looking at how to include the security company as this is outsourced. Reviewing our existing resources Myth Buster Quiz and autism posters. Worthing and Adur Council are potential partners to take forward ideas as a Disability Confident Employer Leader.

### **6. Date of next meeting: 19<sup>th</sup> May 11am – 1pm.**

Meeting closed at 1pm.