



# Autism Partnership Board

## Minutes

**Meeting:** Thursday 4<sup>th</sup> February 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 – LIMA, Aldingbourne Trust  
Mike Smith – Commissioning Team WSCC  
Roxanne Hall – Asperger’s Voice  
David Henderson – ASSA

**Guests:**

Mark Dow (WSCC, Head of Strategic Housing, Adults and Health)  
Chris Harris (WSCC – Senior Contracts and Commissioning Manager, Mental Health)

**Apologies:**

Mark Bushby – Independent advocate  
Bodil Scrivens – Parent carer  
Caroline Sawkins - Asperger’s Voice  
Dan Gregory – Asperger’s Voice  
Julian Morgan – Independent advocate, Autistic UK Director  
Warren Ball – Autism Specialist (SPFT)  
Joel Benson – ASSA  
Dr Dawn Howard – Clinical Lead Neurodevelopmental Services (SPFT)  
Graham Sargent – ASSA  
Pete Ring - ASSA

### Notes and Actions

#### 1. Introductions

There are Rep changes from the self-advocacy groups as follows: Aspergers Voice now represented by Roxanne, Dan and Caroline and ASSA by David, Pete, Anna and Joel.

James has stepped down after many years' service on the APB and he was thanked for his valued work and wished all the very best.

## **2. Matters arising from 04/12/20**

Page 2 & 3 - Sessions held in January between self-advocacy groups, carers and Healthwatch so that views can be fed into the Sussex NHS Learning Disability and Autism Strategy. A contact has now been established with Healthwatch that will involve groups in future consultations. Impact shared with Healthwatch the GP Quality Check Report. Survey links were shared with the APB minutes.

Page 8 - Feedback from Aspergers Voice about access to social care support and getting through to Lifelong Services. Feedback shared with the Operations Manager for Lifelong Services. Colleagues in CarePoint (CarePoint is the telephone and online 'front door' for adult social care) have been involved and a review of the process and pathway completed. To take this further and do a deeper dive it would be necessary to have specific case examples.

WSCC web information has been reviewed. The County Council's website autism 'landing page' does not have any specific information but instead signposts you to the Connect to Support website. On Connect to Support the Autism information pages were developed by self-advocates in 2019. Scope for more information to be added to 'landing page' and suggested reviewing Connect to Support. ASSA and Aspergers Voice to input into new content.

Aspergers Voice suggested a Lifelong Service Leaflet/information should be considered and this is being looked at. Lifelong Service is a part of Adult Social Care.

Page 8 – Members asked for a 6<sup>th</sup> APB meeting date which has been found. The meeting dates for the year are: 4<sup>th</sup> February, 22<sup>nd</sup> April, 22<sup>nd</sup> July, 2<sup>nd</sup> September, 7<sup>th</sup> October and 2<sup>nd</sup> December.

Page 9 – partial answer to question about the [Sussex Covid-19 vaccination programme](#).

Question about reasonable adjustments and what people can ask for and expect. There is some [NHS Covid guidance](#). Case by case requirements to be flagged with GP. There is advocacy support for people who have difficulties. Question was about person with OCD and would need a home visit but injection in garden because worried about people coming into the house.

**Action:** Ask what the approach will be by vaccination teams in such a case (Lisa).

### 3. Housing Discussion

Mark Dow and Chris Harris joined as guests for this discussion. 2 slides with some housing data was shared.

Slide 1: National Picture - There are 1,583,068 social housing units in England & Wales. At any one time 25,262 are vacant. This represents 1.6% of the total stock. 1,146,097 households waiting on Housing Registers.

Slide 2: West Sussex Position - 14,204 social housing units owned by local councils. 8,072 owned by Crawley Borough Council. 3 out of 7 local authorities have retained housing stock. 126 vacancies at any given time – 0.88% of the stock. 9421 households waiting on Housing Registers. 910 homeless families in temporary accommodation.

Facts and figures for West Sussex are bleak and show that there is severe pressure on social housing. The current availability is only enough to house the number of people in temporary accommodation.

Housing Lead will take back key messages from the APB to the housing forums as it's important to raise autism awareness of housing needs and listen to what's needed.

A positive recent development is a jointly agreed Memorandum of Understanding (MOU). This is a high-level statement of intent where following organisations will work together to look at accommodation need and get better outcomes: NHS - CCG, SPFT, WSCC – Social Care, District and Borough's.

Members said that many autistic people need stability, they do not want to move around, and they want the security of tenure, so they do not have to worry about having a safe place to live.

Members said noise can be an important factor. In one place a self-advocate lived she got very little sleep because she could hear noises from neighbours. Autistic people have sensory needs that can lead to anxiety or mental ill health if not addressed.

Only 15% of autistic people are employed and so affordability is an important consideration. However, 'affordable Housing' did not necessarily mean affordable to people on benefits.

Highly specialist services for autistic people with mental ill health being discharged from hospital, secure or out of county, are being developed both through existing and new placements in residential care or supported living schemes.

About 2.5 years ago there was some mapping work completed with family carers and autistic people to understand what specialist accommodation should look like. They thought about general needs, environment design and types of support such as floating.

Members agreed that this work had been good, and the information gathered important. However, many of the carers involved feel that not much has changed for them and they are still in same situation years later. Many carers have adult children living at home but would like them to be living a more independent life in their own homes.

Details of [new builds in Oxfordshire](#) that had been designed for autistic people. Members asked if it was possible to influence the design of new build social housing? The Housing Lead said in theory the District and Boroughs could consider planning applications when over a certain number of units however successive administrations had weakened the influence of local councils.

The APB Quality Check Report was shared this was completed in 2017 and still has some important recommendations which are relevant and shouldn't be lost.

Members asked if being on the Housing Register was important. The Housing Lead said it was if people want to live in social housing and this is how the Districts and Boroughs determine how much is needed, if not on register then sitting below the radar.

When the APB looked at the Housing Application process previously, they found that each District and Borough had a different form. On one example there was a question 'Do you have a Disability'. This was problematic because autistic people may answer this question 'no' and they will not then have an opportunity to say how their life is impacted.

**Action:** Check with each District and Borough how autism is captured (Mark).

Members said that the MOU is an opportunity to share information across the organisations including concerns that young adults are not able to live a more independent life, ideal designs for units, and numbers of social units needed.

Self advocate said that when she had moved up to the highest banding, she was offered housing and there was pressure to decide quickly or lose out or be moved to a lower banding again. This felt pressure to make a quick decision and led to her moving to accommodation that wasn't right and it failed after a few months because it was unsuitable for her sensory needs.

It was agreed it would be helpful to know what reasonable adjustments are being made in the social housing process.

Should people on TCP Register who move into private accommodation be on register for social housing as the private landlord may not be a long-term solution. Private Landlords may not have any autism awareness. Housing lead said that there are Landlord Forums where autism awareness information can be shared.

ASPIE trainers did some training with one of the District and Boroughs housing teams and would it be worth promoting again.

**Action:** ASPIE Trainers to take forward housing teams training (Harriet)

**Action:** Take forward feedback including APB quality Check and Carers Consultation (Mark).

Mark and Chris were thanked for their time and asked for regular updates for the APB.

#### **4. Member Updates**

ASPIE Trainers have been busy delivering online training sessions as part of the [Health Education England and MIND Winter/Spring programme](#).

Andy West is covering for 3 months whilst Impact recruited to Supporters vacant post.

CSWS are holding monthly workshops for carers up until June 2021. Aware of an increasing number of carers who are receiving an autism diagnosis themselves. CSWS will look to see if a group for autistic carers is needed. Carers support groups continue to meet online and there is a monthly carers newsletter. DWP have recently attended carers group and they have Healthwatch lined up. Housing Register information will be promoted when the process is clearer.

Member said they had received an autism diagnosis in late 60's. Since then they have actively looked to understand autism better and are very keen to get involved with any research taking place. Has experienced some 'ageism' and told too old for some research projects because there is no one to compare results with. Involved with SPFT Research group and has also been in contact with Professor Happe at Kings College. There is a recording from last year's [Brighton and Sussex medical school event](#) which might be of interest.

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

Mental Health, impact of the pandemic, anxiety and what support is or isn't available in community.

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

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