



West Sussex Autism Partnership Board (APB) Minutes

Meeting: Thursday 22nd September 2022, 11am – 1pm (online Zoom)

Attendees:

Lisa Loveman (Chair) – Commissioning Manager (WSSC)

Anna Lansley – ASSA; Aspie Trainer

Jayne Simpson – Parent carer

Mike Smith – Commissioning Officer (WSSC)

Dan Gregory – Asperger’s Voice

Harriet Wilson - Impact Advocacy

Bodil Scrivens – Parent carer

Rosie Froget - Impact Advocacy Supporter for Aspergers Voice

Maggie - Asperger’s Voice

Vicky Littlejohn – ASSA

Lucy Watson – Carers’ Wellbeing Support Worker for Carers of Autistic Adults (CSWS)

Catherine McGill - Co-production Lead West Sussex, Capital Project Trust

Guests:

Diana Bernhardt – Senior Commissioning Manager, WSSC

James Ironside - Policy and Data Protection Manager, WSSC

Charlie Young – Projects Manager, Bognor and Chichester Citizen Advice

Apologies:

Dr Dawn Howard – Clinical Lead Neurodevelopmental Services (SPFT)

Pranay Chakravorti - Interim Senior Mental Health Commissioning Manager (West Sussex CCG)

Katie Green – Asperger’s Voice

Graham Sargent – ASSA

Mark Bushby – Independent self-advocate

David Henderson – ASSA

Roxanne Hall – Asperger’s Voice

Warren Ball – Autism Specialist (SPFT)

Andy West – Impact Advocacy Supporter for ASSA

Martin Ford – Aldingbourne Trust (manager of My Network & LIMA services)

Notes and Actions

1. Welcome and Introductions

Guest welcomed, everyone introduced themselves and apologies were recorded.

2. Update on actions from 21/07/22

Page 2: ASSA and Aspergers Voice are still planning to hold a joint meeting.
Action: carried over.

Page 2: Maggie and Anna to join Customer and Carers Group. Maggie's first meeting is early October. Anna is waiting to hear back from WSCC.
Action: James will chase his team to respond to Anna.

Page 3: Maternity item to roll over to future meeting when space on agenda allows.

Page 5: Review Leaflet circulated. Team Manager to be invited for updated to a future meeting.

Page 6: David shared prefabricated construction information.

Page 7: No update on Time to Talk.
Action Pranay to provide - action rolled over.

Following a couple of amendments on the attendance list the minutes of the meeting held on 21st July 2022 were approved as a correct record and there were no objections to them being published on the WSCC APB webpage.

3. Redesigning access to adult social care

James shared introductory film about this work in advance of the meeting.

This project is not yet linked into the community transformation programme but there are overlaps and interdependencies. James and Catherine will connect outside of APB.

Discussion:

APB members discussed things that would help autistic adults:

Consideration of impaired executive functioning - this can prevent people getting started, knowing where to start, following a process/pathway, understanding what happens if get diverted or 'cancelled', for example, some people are unable to make appointments.

Simple guides that chunk information into bite sized pieces. What you need to do when and what will happen next.

Someone to help you navigate the system. You may not know what information you need to give and what will help open doors and access support. The Changing Futures programme is looking at creating service 'navigators', as guides through this kind of thing. Peer support can also help for people without family or friends to support.

Chat rooms or automated responses can have a limited range of responses, and these response would need to be autism friendly. Self-referral forms can be difficult as questions can be misunderstood and led to anxiety.

No wrong door. People do not want to be pushed from pillar to post and repeat information over again.

Well trained staff who understand autism and know what the pathways are. A navigator role would help when there are multiple handovers.

Simple pathway – too many steps to reach the goal increases chance person will not access support they need.

Flexible – not set in stone but can flex to meet individual needs.

Being clear about timescales – things seem to take much longer than expected – ‘have I been forgotten?’ ‘How long is it supposed to take?’ Doesn’t have to be a guarantee and could be different times when busy period. When told that something is going to happen and then it doesn’t can impact on person’s anxiety ‘Don’t make promises you can’t keep’.

Visual representation of the pathway.

Information is up to date, and this doesn’t rely on lots of organisations updating their own information.

If things must change communicating this with a clear explanation.

People build trusting relationships with professionals, and it helps if they can talk to them rather than someone they don’t know.

Waiting lists – having a specific contact to follow up with, rather than waiting/wondering who will get back to you and when.

Acknowledgment that some people have poor memory and do not retain information. Perhaps a summary email being sent after a call which could include a list of bullet points, and a list of future actions for them and for me.

Next steps – James will be leading on a Collaborative Working Group who will steer the coproduction/engagement work. Membership will be voluntary sector, partnership groups and service users. Proposing 3 parts to the Groups work:

- Mapping the ‘As is’ and what’s working well or not so well.
- Looking at what options there are to do things differently.
- Reviewing the information, advice, and guidance.

People will be paid who are part of this work. Payment is at NMW, and this can be via BACS, voucher or donation to a given charity. James can also involve the

self-advocacy groups in other ways and is open to suggestions. Catherine can help James's access people who have not been able to access the services.

James contact details are: james.ironside@westsussex.gov.uk

Action: James to share a specification for the collaborative working group.

Actions: ASSA and Aspergers Voice to ask Groups how best to involve.

4. West Sussex Plan for Autism Week 2023

There was a plan for an event in 2020 that involved autistic people speaking about their lived experience to professionals. It got cancelled due to Covid. This could be looked at again with people's stories being recorded and shared, perhaps one story for each day of the week. Could we link to the awareness raising work that ASSA are doing? To discuss ideas/plan at November meeting.

Actions: ASSA and Aspergers Voice to ask Groups if this is the best idea.

5. Cost of Living concerns

Charlie Young shared her [presentation](#).

Things are changing all the time with government announcements about extra support but also interest rates rising and new economic pressures. Latest on energy bills is fixed price on gas and electric tariffs. This has helped but still means people are paying significantly more.

Grant of £400 paid to person whose name is on the bill. Further announcement due tomorrow.

Citizen Advice have leaflets which you can request including 'should I get a smart meter' and 'how can I save money on bills'. Citizen Advice campaigning now for people with disability and health conditions who do not have an option of cutting usage.

There are 2 cost of living payments to those on benefits to save towards cost-of-living increases.

Waiting for announcement on the Household Support Fund (phase 3 Oct 2022 - March 2023). In phase 2 WSCC used the money towards the Community Hub, Free School Meals, Foodbanks and through grants to voluntary sector. WSCC staff need to know about the Household Support Fund.

Small changes at home can save a bit of money. Discussed: 'Powerdown' is a plug for up to 3 appliances. Citizen Advice are hoping to get some more of these.

Shower rather than bath – self advocate pointed out this was not feasible for everyone. Sensory issues can mean need to use more heating.

Self-advocate pointed out cooking was her special interest and good for mental health. She might spend more on this but hasn't got other high expenditure.

Charlie advised that if you need to use a lot of water then you can ask the water company for their discount scheme where they give you a special tariff and cap water amount.

Self-advocate described being nocturnal so uses more electricity at night.

Self-advocate had experience of using citizen advice service. Initial conversation with volunteers were limited to signposting however did get referred to a specialist adviser who then gave invaluable support that wasn't time limited. Charlie said branches are affiliated to Citizen advice so model may vary from office to office. Chichester and Arun have a home visiting service where you get a 1:1 adviser.

Charlie said energy and water companies are not proactive so you need to tell them that you are struggling. Once they know there are things they can do to help. Citizen Advice can help if contacting them is difficult. Important not to let your house get too cold as that can lead to other health problems. Charlie shared a [paper](#) with the tips discussed today.

Self-advocate shared a tip to use a dehumidifier and she says it makes the house feel warmer and clothes dry quicker, she also recommended Radflek radiator reflectors which prevent heat loss from back of radiators.

From the chat - Carer wrote that if you have care needs and contribute to your care charges you may be able to get these reduced if your energy bills are higher due to your needs. This is seen as Disability Related Expenditure. WSCC Financial Assessment Team told carer reduced charges if your energy bills totalled more than £1282 per year - WBA.dutyworker@westsussex.gov.uk

6. Introduction to the pulling together 'lived experience' network in West Sussex

Catherine McGill shared her [presentation](#).

There are lots of changes taking place in the NHS. Phil Shackell came to the last APB to talk about the Community Mental Health Transformation Programme. Under Physical Health there is also the Changing Futures Programme. Lots of opportunities to involve people with lived experience but this requires some coordination otherwise risks duplication of effort and potential for the same people to be asked or some people left out.

Catherine's post is for 12 months, and she has a counterpart called Tasha who is covering East Sussex and Brighton and Hove. They are specifically working on the Community Transformation Programme, but they are going to make sure they are linking in with the other programmes including the one James has talked about today and SPFT's lived experience programme.

Catherine is setting up and recruiting to an advisory group (paid positions for people with lived experience). There are 3 priorities:

- Learning Together: supporting people to participate – may need help developing skills to participate; colleagues may need skills to involve; practical considerations to enable participation such as payments.
- Shifting Power: Shifting power from clinicians so wider viewpoints are included and equally valued. This will involve some myth busting about inclusion that allay fears e.g., around triggering and trauma informed working.
- Network of Ambassadors: People who can champion lived experience and ensure people are fully involved.

Agreed that Catherine could have a regular update slot at the APB.

Lisa suggested linking with Supported Employment West Sussex (SEWS) who have autistic people on books actively looking for paid work.

7. Updates and AOB

- ASSA update

ASSA have a new focus group working on a campaign called 'Disabled Autistics Matter'. Self-advocate explained why ASSA wanted to challenge the popular/media narrative that gets most attention 'neurodiversity is not a disability but an ideology'; there are high profile and successful people in the media who are part of the conversation and people who are more marginalised are not being heard; 'it's wrong to talk about deficits it's about differences'; 'you can lead a normal life'. This narrative ignores people who have never had a job, a relationship, or lived independently. It also does not take account those that are significantly impaired because of their autism, sensory needs and who also may be non-verbal. These deficits are not talked about and can prevent autistic people getting access to support. People with a learning disability and autism are often left out altogether.

ASSA are planning a website, social media campaign and asking NAS to be more inclusive of people with a range of needs or people that can represent them on their advisory groups.

Action: Lisa to add longer item for longer update at next APB and will invite colleagues from the comms teams to attend as guests to next APB.

- Mental Health Quality Check – no time to discuss today. Please send any comments on the quality check briefing to diana.bernhardt@westsussex.gov.uk
- Dogs for Autism – agreed to a presentation at February meeting.

Action: Jayne offered to request speaker from Dogs for Autism.

8. Date of next meeting: 17th November 11am – 1pm online.

Meeting closed at 1.15pm.