



West Sussex Autism Partnership Board (APB) Minutes

Meeting: Thursday 21st July 2022, 11am – 1pm (online Zoom)

Attendees:

Lisa Loveman (Chair) – Commissioning Manager (WSCC)

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 (WSCC)

Dan Gregory – Asperger’s Voice

Mark Bushby – Independent self-advocate

Bodil Scrivens – Parent carer

Rosie Froget - Impact Advocacy Supporter for Aspergers Voice

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

David Henderson – ASSA

Roxanne Hall – Asperger’s Voice

Warren Ball – Autism Specialist (SPFT)

Maggie - Asperger’s Voice

Guests:

Terry McDermott – Service Manager Lifelong Services, WSCC

Diana Bernhardt – Senior Commissioning Manager, WSCC

Phil Shackell – Interim Deputy Head of Mental Health Commissioning (West) NHS Sussex

Apologies:

Dr Dawn Howard – Clinical Lead Neurodevelopmental Services (SPFT)

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

Katie Green – ASSA

Graham Sargent – ASSA

Harriet Wilson - Impact Advocacy

Notes and Actions

1. Welcome and Introductions

New member Lucy Watson welcomed. Lucy is representing Carers Support West Sussex (CSWS) as the autism lead. Lucy organises carers support groups, produces a newsletter, and attends strategic meetings representing carer issues. Note: the ‘carers offer’ was covered in our last meeting in May.

Guest welcomed – Diana Bernhardt - Phil Shackell and Terry McDermott joined later.

2. Update on actions from 19/05/22

There were no actions to report back on or any matters arising. The minutes of the meeting held on 19th May 2022 were approved as a correct record and there were no objections to them being published on the WSCC APB webpage.

3. Update from Members

ASSA updated on a new focus group looking at 2 issues which members think are important. The first is how best to raise awareness of autistic adults with higher support needs as these individuals often find it difficult to access support or peer groups. The group want to include how the voice of autistic adults with higher support needs can be heard. ASSA are looking at their own group and any changes they could make to support access but also outward facing and raising awareness. Secondly, ASSA are wanting to counter-challenge the neurodiverse narrative that autism is not a disability/disorder or impairment and is a difference or special talent. ASSA thinks this narrative could be damaging to those autistic people who rely on benefits and funded support. ASSA has already updated webpages.

Aspergers Voice are very interested in what ASSA are doing and there is cross-over with work underway in their group. Aspergers Voice asked if the 2 groups could get together to share ideas.

Action: Andy will take Aspergers Voice request for a joint meeting back to the focus group to agree.

Aspergers Voice have surveyed all its members. The committee have started addressing the points made in the feedback including sharing more information with members through a newsletter.

Parent carer updated that she has joined the WSCC Customer and Carer Group. The Group is seeking more people with lived experience to join. The meetings going forward will be held face to face and online - hybrid. To note: as part of the WSCC commissioning review Lisa has asked if the governance arrangements and how information flows in and out of the different engagement groups/boards can be formalised.

Action: Lisa to put Anna in touch with the organiser o the Customer and Carer Group, Ruth Corden.

Parent carer feedback about the annual [Autistica's Research Festival](#). Recording will be available at later date. Interesting research about maternity care being done by Birmingham University. This is not an area that the APB have ever

looked at and as female autism diagnosis is increasing its an important area to have in our sights.

Member has personal experience of maternity care and is also a trainee midwife and has not found any specific clinical guidance around autistic mothers. Agreed that this would be a good topic to pick up later in year.

Action: Lisa and Rosie to begin scoping who best to talk to APB about maternity services.

4. Update on social care reviews

Terry McDermott gave a presentation, and the slides can be downloaded [here](#).

Terry is a Service Manager in Lifelong Services (part of Adult Social Care). Terry gave some background to why a new Review Team has been established.

Terry said there are over 2,400 adult customers in Lifelong Services (LLS) with long term services, many of whom are autistic. There are a lot of people to review in a year and the service haven't been very good at seeing everyone over a 12-month period. The past few years have been challenging for all sorts of reasons and the teams have had to prioritise people in high need or in crisis.

When people's support has been reviewed it had tended to be for adults who are coming to social care saying things have gone wrong or their needs have changed significantly, or they are in urgent need (in crisis).

The service knows there are lots of people who have support and haven't been reviewed, who aren't in contact and in these cases its assumed things are ok, but there is no way of knowing if the support being provided is still meeting their needs and outcomes.

This review work is informed by: The West Sussex Council Plan which sets out the priorities for the local authority over a 4-year period; Adult Social Care spoke to customers, staff and providers and wrote a strategy of what people wanted from their care, and how the department will deliver this; and finally, the Adult Services Business Plan sets out the priorities and focus for this year.

Lots of challenges in social care delivery. On the national news this week, many Directors of adult social care are saying this will be the most challenging year ever and they are being asked to do more with less. This work is about how do we get the best from our limited resources and meet people's needs for a 'good life'.

Strengths-based approaches focus on what individuals and communities have and how they can work together, rather than on what individuals don't have or can't do. Historically social care has tended to work from a deficit model, people come with problems, or a list of things that do not work for them. Social workers emphasise the problems to seek funding. A strengths-based approach

works with the individual, highlighting their abilities rather than making the deficit (what's wrong) the focus of the intervention.

5. Discussion:

Self-advocate said it was important to remember that some people have no networks to draw support from including no family or friends. Terry responded that reviewers are aware that people may need support from an advocacy service.

Self-advocate asked what the consequences for the council were if somethings they 'must' do under the Care Act are not done. Terry said that in addition to missing opportunities to prevent or reduce needs and complaints, the council will be subject next year to an inspection by CQC under the new inspection regime.

Parent carer was pleased that the quality and appropriateness of a support plan was going to be checked. What would happen where someone already had an allocated social worker who they knew well and there was a relationship of trust. Terry said that this allocated worker would carry on holding the review. Parent carer was pleased about this approach but said some of the existing social care staff could do with some autism training. Terry said that all staff have had training in the strength's-based approach and autism training was available to staff. The review team come from a variety of backgrounds, and they will try to match those with appropriate autism experience.

Self-advocate said she was unhappy with the use of strength-based approach for neurodiversity, and it is rather patronising. People can have a good awareness of things they can do, and they want statutory services to help them with the things they can't do or struggle with. This approach is saying having support is a bad thing and asked if it was more about making savings. Terry said the reviews would not ignore what someone can't do and would look at what is preventing the person from having a good life or achieving their aspirations.

Self-advocate asked how people find out about lifelong services. He remembers the PAT team, a predecessor of Lifelong services, and they had a leaflet. Lisa said that a new programme of work is starting about redesigning the access to adult social care. The team are wanting to coproduce this and will come to the September APB to discuss this programme at an early stage and get a steer from member. Between now and September self-advocates can think about the important messages.

Parent carer said the assessment process takes a long time and this can impact on the wellbeing of the autistic adult. Her current experience is the assessment visit took place in April, there has been a follow-up call and first draft reviewed but still waiting for the signed off assessment. Terry offered to take this up

outside of the meeting. Another new team called Combined Placement Sourcing Team will find suitable services or options for meeting outcomes.

Self-advocate said she was concerned that a strength-based approach might not be sustainable in longer-term. For example, person has been able to do something and then they start to struggle again. Terry agreed that it was important to review a change in support to check benefits or outcomes being realised and no unintended consequences. Another self-advocate agreed that even things you are good at can be impacted by your autism and you can not divorce one from the other.

Action: Lisa will circulate the Review Leaflet with the minutes.

Action: Lisa to invite Sam Robinson, Review Team Manager, to update APB towards end of year.

6. Update on commissioning specialist accommodation services

Diana Bernhardt shared a presentation slide which can be downloaded [here](#).

Updating on work to increase options for accommodation and support of autistic people with highly complex presentations. Diana said that there are other accommodation and support gaps, but this complex support is a priority as we know we have a gap in provision in West Sussex.

Using the West Sussex Supported Living Framework (this is a contract) there has been a market event asking for proposals from suitable providers. The Framework provides a specification for complex and specialist support. Providers also arrange the accommodation through tenancy agreements and sometimes housing they own or through landlords.

Anonymised cases studies were shared at the event and included people with learning disability and autism, autism, no learning disability and mental health, and autism and a forensic history.

Next step is for commissioners to meet individually with organisations to look at their proposals. Some organisations will have a property already or they may need to source this. The property development and recruiting the staff team mean schemes will take at least 6-months to mobilise. Part of the discussion with providers is how they will involve service users, families, or people with lived experience in the development of the scheme.

Parent carer was concerned about the wait for new schemes to come online. Diana said that we will continue to look at existing vacancies for urgent referrals and that commissioners had particularly focussed on people coming through transitions or in specialist hospital beds who will need accommodation in the medium term.

Parent carer had worked with mental health commissioner in 2018 to look at the gold standard for this type of complex scheme. Lisa said this earlier work

was used to inform the Supported Living Framework which is now a combined LLS and Mental Health contract and has Lot 3 which is complex and specialist provision.

Parent carer said her experience was a placement that was not 100% ideal but was all that was available. Diana said the review process discussed earlier was crucial in checking the current provision is right and flagging with commissioning if a plan is needed to place somewhere more appropriate.

Self-advocate said there are lots of creative accommodation solutions and had heard of a Midlands company who makes pre-configured units which are also autism friendly design. Diana was interested to learn more about this option although finding land can be an issue.

Action: David to email Diana company details.

7. Task Group updates

This item was not discussed because of time pressures but updates will be shared by email with the board.

8. Redesigning access to adult social care

Covered under item 4.

9. Update on Mental Health community Transformation Programme

Phil Shackell updated the APB on the national NHS community mental health transformation programme. In advance of the meeting, he shared a [film](#) about the programme for background information.

The high-level aim of the programme is to work differently so that mental health support is delivered in an integrated way and not as it is now, in silos. The aim is for there to be no wrong front door and a seamless handover if another service area needs to be engaged.

The programme involves the NHS, voluntary sector, social care, and the mental health trust. Katie Glover from West Sussex MIND co-chairs the West's community transformation group. This group wants people who use mental health services to be involved from the beginning with design and delivery. The group has recognised that autistic people may need their mental health supported in a different way and want to specify this in the mental health pathway. There is also a recognition that the workforce needs to be skilled up and that autism expertise is not across all areas/services.

Phil has some transformation funding to support this work and is asking the APB what is needed to put it right?

Parent carer said it can take an autistic person a long time to build up trust and the current treatment pathways are time limited, for example, Time to Talk, if you do not engage the intervention can be ended.

Parent carer said the route into Time to Talk is through use of questionnaires which autistic people can find very difficult to complete.

Parent carer said Cognitive Behaviour Therapy is a preferred options and if delivery is not adapted for autistic person, it's not workable.

Action: Phil is going to feed this back to Pranay who commissions Time to Talk and ask him to update at next meeting.

Warren said he sees people in the autism diagnostic service who have often been known to other mental health teams for a long-time (for example, emotionally unstable personality disorder or borderline personality disorder). There is a need to understand the differences in the conditions more clearly and he would advocate for autism screening at a much earlier stage before people go down the wrong path.

Self-advocate says getting an autism diagnosis can be life changing and the APB have been concerned for a long time about the 3+ year waiting time. The diagnosis will bring insight into how services can support the person well and make reasonable adjustments.

Warren said that there needs to be improved consistency of care in mental health services and more expertise around neurodiversity. His service doesn't have capacity to do this and there are also workforce issues.

Self-advocate asked if there were any timescales for commissioning what's needed. Phil said no, he can ring-fence the funding and it can take time to work out the best plan.

Lisa said that the programme has funded a Coproduction Lead post managed by Capital Project Trust. Catherine McGill has been appointed and she would like to come to the APB next meeting to feedback about how she is going to do this work.

Self-advocate said that for most autistic adults' recovery is not attainable and they will not be free from the anxiety which lies behind their mental health issues. It should be more about managing how the mental health issues are connected to autism so that they can improve their quality of life.

Self-advocate recommended commissioning Aspie Trainers, a local autism lead training organisation who can work in partnership and deliver a wide range of high-quality training sessions. This would also support the employment of West Sussex autistic residents.

Parent carer said that Sussex had an Autism specialist team that delivers great results but is only available to a very limited cohort. Her experience of TCAT

was that there was a successful discharge from inpatient stay after previous failed discharges. However, in a community placement TCAT not available and it is going through a rocky patch and ideally TCAT would step in to support but they only work with acute need, generally mental health ATS can't meet same need and think that because someone has a large social care package this should cover things. However, the social care does not cover mental health support. Phil said he could see how there could be core community services which has specialist clinical support graphed on.

Self-advocate said one of the features of autism was difficulty accessing social support and making friends. This in turn leads to isolation and can lead to increased anxiety. Increasing the number of peer support groups and support to access them would be good preventative measure.

Self-advocate said some autistic adults have special interests which help reduce anxiety. Support with special interests could help.

Parent carer asked Warren what is the pathway for an ADHD diagnosis? Warren said unlike East Sussex and Brighton and Hove the West Sussex autism diagnostic service could not assess for ADHD, Dyspraxia, or other neurodiverse conditions. These are separate pathways and referrals are through the GP.

Warren shared research work by doctor Jess Eccles, who presented her recent research on mind/body connections and hypermobility in neurodiverse conditions on Radio 4 earlier this week:

<https://www.bbc.co.uk/sounds/play/m00199ym> There will be a pilot on 'bendy bodies' later in the year.

10. Any other business

There was not time to cover any other business.

11. Date of next meeting: 22nd September 11am – 1pm online.

Meeting closed at 1pm.