



West Sussex Autism Partnership Board (APB) Minutes

Meeting: Thursday 23 May 2024, 11am – 1pm (hybrid: zoom and Chichester County Hall)

Attendees:

Diana Bernhardt – Commissioning Service Manager (WSCC) Chair
Anna Lansley – ASSA, Aspie Trainer
Graham Sargent – ASSA
Maggie – Aspective
Jayne Simpson – Parent carer
Lorna Bradley – Carers Support West Sussex
Martin Ford – Aldingbourne Trust, LIMA
Jess Dare – NHS
Sandjea-Marie Adassa – (WSCC)
Ed Armstrong – Commissioning Manager (WSCC) Minutes
Judith Packer – Commissioning Lead (WSCC)
Simona Giunta – Commissioning and Contracts Officer (WSCC)
Gary Capelin – Peer Support Co-Ordinator (WSCC)
Katie Glover (WSCC)

Apologies:

Vicky Littlejohn, Dan Gregory, Sheryl Bunting, NDS Service

Notes and Actions

1. Welcome and Introductions

New attendees introduced themselves and apologies were recorded.
Sandjea-Marie Adassa (WSCC) and Judith Packer (WSCC) – presenters.
Lorna Bradley – attending for Carers Network.
Board informed that a Bodil Scrivens, parent carer representative, had resigned from the board. They asked that message read out: “please convey my best wishes to everyone on the board, especially self-advocates – I have so much admiration for their willingness to share their struggles and fight for improved services for all autistic adults in the county”

2. Last meeting notes

Minutes of the last meeting approved with the following corrections:

Page 2 Request to change “members felt left out” to “members were left out.”

Section 5 – Amend minutes to clarify that Lucie Venables had said that there would be a 2024 year of Autism which would include events around the county.

Diana updated the meeting that the work to develop the autism strategy had commenced. The year of autism would form part of that work and suggested we may need a sub-group to plan the events and ask who would be interested.

A member asked if the work would be paid, Diana clarified that this would depend on what functions people were carrying out. Attending meetings would be unlikely to be paid.

A member raised that there is a lack of consistency regarding what people with lived experience were paid for. James Ironside had referred to guidance published by West Sussex County Council.

Katie G agreed that she will speak to James Ironside regarding the council guidance.

Maggie, Graham and Anna indicated they would like to be involved in planning events and suggested Vicky may also be interested.

Matters arising

1. Simona to circulate the meeting planner. Complete.
2. Reviewing APB terms of reference to confirm coproduction role of the board : Agreed to discuss terms of reference at the next APB meeting.
3. Members to indicate if they are interested in joining the Autism strategy steering group. Complete. A member indicated they would still like to be involved but had heard that membership of the steering group was now closed. Katie G said she was happy to review this.
4. Travel expenses – it was clarified that if people do incur expenses to travel to meetings such as the APB and the Autism strategy meetings the Council **will** reimburse such expenses. If people are likely to need payment, it would be helpful to let Simona know in advance.
5. Support provided to the self-advocacy Groups by Independent Lives – Diana confirmed this has been extended by 2 months until the end of May.

3. Autism Strategy update

An update on the autism strategy from the autism strategy group will be a standing item on the APB agenda.

A member of the steering group provided a verbal update.

Katie Glover is leading on the development of the autism strategy.

1st meeting of the steering group held on 9th May with representation from LIMA, ASSA, Customers & Carers Group and Carers Support. The meeting discussed membership, terms of reference and looked at the work that ESCC are carrying out to develop their local autism strategy.

The steering group is concerned that the group did not get too large but important to ensure all relevant stakeholders are represented such as people who use services, family carers, providers and other relevant stakeholders.

Katie G fed back she felt it was a positive first meeting and the minutes will be shared with the papers from the APB with papers for the meeting beginning of June will go out next week.

Katie G is drafting a stakeholder map to discuss at the next meeting.

It was felt that whilst the steering group needs to be a workable size it could remain open to members of SAGs.

4. [Presentation on Early Support](#) – Sandjea-Marie Adassa

Sandjea thanked members of the Self-advocacy groups for their feedback so far. Sandjea presented slides on early support to seek feedback from Board members on what worked well and service gaps.

We want better understanding of what the gaps and barriers are before looking for solutions.

Activity 1 – write down as many different places and ways you think the Council could help you find information so that you can get help for things as early as possible.

Summarised members' feedback:

- Concern around Autism and communication issues. Highly verbal people can still be vulnerable, assumptions about communication pose a challenge. Self-advocate was discharged by a service due to not responding to emails which is one of their support needs. Lack of response from an autistic person may need to raise an alert around safeguarding/welfare checking.
- Self-advocate commented that society assumes most people have someone which is not always true
- Parent carer: communication issues and time-limited offers of support or interventions are common themes with many Mental health services, NHS, organisations. Also important that organisations accept communication with autistic people can be very variable. Provision that meets specific autistic support needs is rare or non-existent.
- Information theme across variety of websites and community services: not presented in autistic-suitable way; non-existent or out of date; inaccurate e.g., parent carer took child to disability swimming session but

there was none. Member experienced local ICB health guidance differing from NICE national guidance.

- General feedback that autistic people and parent carers often feel hopeless about accessing appropriate services

Activity 2 – how could early support be better? What could make things work better?

Summarised members' feedback:

- Member experienced no reply/answer from a service for months. Waiting list to get any support was very long. Could improve by ensuring a response and shorter waiting lists.
- Information of things on offer on websites are often aspirational. Parent carers would find specific, clear and realistic information on what is on offer rather than generic statements.
- Accessibility: a lot of services only provide support to those with funded care packages or those who self-fund. Ambiguity and inconsistencies for wide variety of autistic people who seek to access services.
- Leisure services staff often unaware of autistic needs. Does not seem that a disability-inclusive service has been commissioned.
- Lack of autism awareness theme – member has been trying to discuss future support provision when elderly parent carer is no longer around for almost 2 years, impact on anxiety levels. Recently getting some support from a mental health service, a bit more assured.

5. Direct Payment Support Service presentation – Judith Packer

Members questions and comments on presentation and issue of Direct Payments:

- Do WSCC need to go out to tender if a contract is running well?
- Member - importance of provider being independent from council but also value in having all services within WSCC, with more staff needed to deliver service in-house.
- Member experience of Direct Payments has not been good. Parent manages it for them. Member would be unable to manage it themselves. Seems DP / Council Managed Budget seems all or nothing, there isn't a third option. Mentioned support worker recruitment challenge now. Overall negative experience of Direct Payments.
- Member without a DP - heard many people say the assessment is difficult and in their experience the Council does anything they can not to provide support. Prefers services provided by the Council. Exceptions for advocacy or where there is a possible conflict of interest. Independence helpful to prevent conflict of interest.
- Information provision – A menu stating what support workers can and can't do would be helpful.
- Parent carer not good experience with Independent Lives last year when it was suggested employing a PA would be a good solution to their

daughter. Experienced challenges re communication from IL, daunted by task of becoming an employer, difficulty sourcing a PA, left thinking employing a PA is not a good fit for them.

- Parent carer - managing DP is a lot of work, even with support from current provider IL. Difficulty employing people the family knows, challenges with that process. Having a means/support to employ people they don't know would be very useful.
- DPs are not very suitable for autistic people because of the skills needed e.g., executive functioning skills. If disability means someone can't work, how are they expected to employ a PA?
- Some people feel local authorities (national not local) trying to shift responsibility onto disabled people and their carers – this work which should be completed centrally.
- DPs are set up with the idea of a helper/enabler not a doer. Having people do things would help member to improve their quality of life.
- Hourly rates of PAs and Support Workers a clear challenge
- Council will try and claw the money back when it isn't spent.

Judith clarified and commented:

- Clarified: current contract commenced 2019, needs to be recommissioned as it is coming to an end and we are legally required to go through procurement to recommission. Some people feeding back change is needed.
- DPs are being reviewed by WSCC as a separate process to DPSS recommissioning.
- DPSS is a statutory service, WSCC seek input to shape future service provision, final decision will need to clear governance.
- Some national work occurring re. pay levels of support workers. DPs were not automatically uplifted: instead people were asked to contact council if they needed an increase.
- Thanked everyone for their helpful inputs and comments. Surveys will be going out in June 2024 and more workshops later in the year if people would like to attend them.

6. AOB

Quality of hybrid format experience today

People attending online had found the background noise made it difficult to hear discussions. Members attending in person had found it difficult to see everyone on screen and did not feel they had any benefit from being in the room in person. It was acknowledged that there was some learning regarding the technology but there was a general preference for an online only meeting. It was therefore agreed for the July meeting to be held online and for this to be kept under review. Diana agreed to speak to the member who had expressed a preference for a hybrid meeting.

LEAP (Post-meeting note to members)

LEAP contact Matthew Moors' post has now ended. If members are still interested in taking part in LEAP activities (See Feb 2024 APB for reference) please contact fiona.streeter@nhs.net

Actions agreed:

Action	Who by	Timescale
Circulate following with May 24 APB minutes: <ul style="list-style-type: none">• Autism Strategy development Group notes• Revised Feb 24 APB minutes	Meeting Administrator Simona Giunta	June 24
Next meeting items: <ul style="list-style-type: none">• Terms of Reference• Autism Strategy Update (standard item until further notice) and Stakeholder Map	Diana Bernhardt - Service Manager Commissioning	June 2024
Follow-up with member about next meeting format (Hybrid/online)	Diana Bernhardt - Service Manager Commissioning	June 2024
Individuals interested in Year of Autism/Autism strategy event to let Diana know.	Members	July 2024
Provide any further feedback and thoughts regarding Early Support presentation to Sandjea-Marie Adassa directly	Members	23 June 2024
Circulate documents ahead of June 24 Autism Strategy Steering Group	Katie Glover	07 June 2024
Circulate DPSS Recommissioning Survey link to APB members	Simona Giunta	End of June 2024

Date of next meeting:

25th July 2024, 11am - 1pm (online, Zoom)
Zoom link will be circulated in early July