



West Sussex Autism Partnership Board (APB) Minutes

Meeting: Thursday 12 September 2024, 11am – 1pm (zoom)

Attendees:

Diana Bernhardt – Commissioning Service Manager (WSCC) Chair
Anna Lansley – ASSA
Vicky Littlejohn – ASSA
Dan Gregory – Aspective
Maggie – Aspective
Katie Green – Access All Areas
Sheryl Bunting – Carers Support West Sussex
Hannah Torr – West Sussex Parent Carer Forum
Jayne Simpson – parent carer
Maxine Harcourt-Kelly – parent carer
Martin Ford – Aldingbourne Trust, LIMA
Megan Oliver – Disability Employment Advisor, DWP
Jess Dare – Talking Therapies NHS
Simona Giunta – Commissioning and Contracts Officer (WSCC)
Gary Capelin – Peer Support Co-Ordinator (WSCC)
Katie Glover (WSCC)

Apologies:

Graham Sargent – ASSA

Notes and Actions

1. Welcome and Introductions

The Board welcomed: Hannah Torr from the West Sussex Parent Carer Forum; Megan Oliver from DWP; Maxine Harcourt-Kelly, Parent Carer.

2. Last meeting notes

Minutes of the last meeting approved. They will be available on WSCC website.

3. Matters arising

All actions from last meeting complete.

4. DWP Employment Support Service [Presentation](#)

Megan Oliver talked about the Disability Employment Advisor (DEA) role in the DWP. There were lots of questions during this presentation. We list the questions and answers separately. Action points noted were either the result of direct questions or after discussion of specific points by members.

Questions:

- Re psychologists that work for the DWP -
Why are they called Work Psychologist and not Occupational Psychologists?
Is their role aimed only at support towards work or also other forms of occupation? What do they do?
At what point do they support people holistically rather than aim towards paid work?
- Can training for DWP about autistic people and people with disabilities be mandatory?
- Self-Advocate commented they accessed DEA support in past. General concern among people with support needs around loss of benefits if they try a volunteer role or part time job and then find they don't cope.
- Parent-carer shared how they supported their daughter to do volunteering. Had to notify DWP. They felt overwhelmed by amount of forms/paperwork to fill which took more hours than the volunteering. Form aimed at establishing what skills the person was learning towards a paid job. Scared by these forms. Each placements collapsed due to lack of appropriate support for their daughter. **Action:** Megan will feed this back up to DWP seniors.
- Self-Advocate asked if need to notify DWP is new requirement. Never heard of before and would find this requirement off putting.
Can we see this list of things that need to be notified to DWP?
- Can DEAs support people with filling in forms?

Answers:

- Megan and other advisors in Worthing DWP are having some training delivered by Aldingbourne Trust about working with autistic people, and those with Learning Disabilities.
Action: Diana to contact DWP Tim to clarify training offer available county-wide to DEAs. Members commented it would be beneficial to have training around neurodiversity, autism and disability available to all DWP branches in West Sussex.
- There is a DEA in each jobcentre and private rooms available
- Specific to Worthing branch: DWP working with education settings to promote and raise awareness of the DEA support role and Universal Credit (UC) among young people with disabilities. Students are accessing this support.

- Re Psychologists:
They attend appointment and case conferences with DEAs.
Customers do not need a diagnosis to access the psychologist.
they cover a wide area and visit individual job centres every 8/9 weeks.
- DEAs can make a referral to psychologist if they feel they need more support with a customer
- Re loss of benefits: some earnings are allowed before benefits are affected. DEAs work with people's specific circumstances, what they think they can do.
- Re volunteering. **Actions:**
Diana to feedback to DWP that volunteering being on this notifiable list is off-putting for customers. Disability support needs fluctuate/go up and down and customers sometimes can feel more able than other times.
Diana to clarify definition of volunteering, is it amount of hours or frequency or nature of it?
Diana to request official list of notifiable changes from Tim.
Megan will feedback how forms that parent carer had to fill were too much and seemed aimed at pushing customer towards paid work in how they were structured
- DEAs cannot support with filling in forms but do refer to CAB. Member shared they had had a good experience with the CAB support.
Action: Diana to contact Anna separately about CAB support

5. Autism Strategy update

Dan gave a general update to the Board. The steering group have agreed on workshops, agreed on the logo, discussed options and content for survey. Katie Glover also presented some [slides](#).

One member expressed lack of trust that the work will lead to positive change. It was clarified that the survey and workshops will reach as many people and groups as possible but individuals can make their own decisions regarding whether they engage or not. Confirmed that Learning Disability Self-advocacy groups will be included, as well as providers, wider public through carer's network and known stakeholders. ASSA and Aspective can forward to their mailing lists.

Katie Glover commented that what could come out of this strategy is to share and evidence the picture of 'this is what it's like for autistic people'. The group could maybe look at areas where they can realistically make a difference. This could even be about changing approaches and culture in schools, not only in terms of money/funding but also in how this area is perceived and approached and seeking to educate.

6. Presentation on review of Terms of Reference – **Diana Bernhardt, WSCC**

Diana explained that the updated version of the terms of reference is in draft form and the final version would need to be approved by the APB.

As there was insufficient time left in the meeting to discuss the draft terms of reference, Diana suggested focusing the discussion on the 2 issues raised by self advocates:

Whether the APB is a decision-making body

Diana explained that no powers had been removed from the APB but the new proposed changes were to clarify what the Board can and can not do. For example, within WSCC there is a legal, democratic decision process for Council decisions. The board is there to influence and articulate feedback from members. There are decisions that we as the Board can make such as how we operate but there will be other decisions for around funding that we cannot make. Self-advocate suggested wording could be that the Board decide how we want to influence but we cannot decide council-wider policies. Parent carer contributed that it's about our voice, representation and being heard while decisions are made by WSCC. In relation of being heard, it was brought up that the Neuro Developmental Service (NDS) have not attended the board for a number of meetings and members ask again if they can be contacted about their representation. **Action:** Diana will contact NDS service.

Member stated that proposed wording seems to reflect how things are, is more transparent about it and commented on how thinking forward may benefit the Board on working together. Other members disagreed. That this group should aim to be closer to where the decisions are made and they affect autistic people's lives.

Voting rights

Some members did not think it was fair that West Sussex County Council should have voting rights. Diana agreed to revisit this issue.

Diana will update the wording and circulate a revised draft to the members to discuss at the next meeting. **Action:** Include ToR in next meeting agenda.

7. AOB

Simona will circulate a request from WSCC for participation in the testing of an AI chatbot.

Member asked about WSCC being notified by CQC for inspection. Diana clarified we know they will come to visit the council, but we do not have a timescale for that

Future agenda items:

Action: Simona to contact Rachel from Aldingbourne to present at next APB.

Action: Diana to clarify issue of payment for those involved in the Workshops.

Action: Diana to request an update on the neurodevelopmental pathway

Action: Simona to contact Autistica and request they attend next meeting.
Martin will provide an Autistica contact.

Actions agreed:

Action	Who by	Timescale
Publish approved July 2024 on website	Meeting Administrator Simona Giunta	Sept 2024
Collate feedback on Terms of Reference item and circulate draft of revised ToR to members.	Diana Bernhardt - Service Manager Commissioning	Oct 2024
Feedback to DWP seniors the issues discussed at APB, specifically re approach of forms around volunteering	Megan Oliver DWP	Oct 2024
Circulate email about Chatbot testing.	Meeting Administrator Simona Giunta	Sept 2024
Contact Tim at DWP re: training offer to all DWPs. Feedback and questions about Volunteering. Request list of notifiable changes.	Diana Bernhardt - Service Manager Commissioning	Oct 2024
Contact ICB to request an update on the Neurodevelopmental pathway	Diana Bernhardt - Service Manager Commissioning	Oct 2024
Contact Anna re CAB support.	Diana Bernhardt - Service Manager Commissioning	Sept 2024
Clarify issue of those who attend the meeting and are not paid with WSCC	Diana Bernhardt - Service Manager Commissioning	Sept 2024
Contact Autistica for attendance at APB	Meeting Administrator Simona Giunta	Sept 2024
Contact Aldingbourne for attendance at APB	Meeting Administrator Simona Giunta	Sept 2024

Date of next meeting:

21 November 2024, 11am - 1pm (online, Zoom)

Zoom link will be circulated 2 weeks prior.