

Cheshire West & Chester Council

Minutes



NOTES FROM ALL-AGE AUTISM AND NEURODIVERGENCE PARTNERSHIP BOARD

DATED 30 OCTOBER 2024

WELCOME AND INTRODUCTIONS:

Oliver Downing welcomed everyone to the meeting and introductions were given.

ACTIONS FROM PREVIOUS MEETING:

The action log was discussed and updated. This will be circulated separately but please note the Terms of Reference although set at the last meeting can be revisited as and when needed.

ACTION 1: Terms of Reference to remain an item for discussion on future agendas.
(Oliver Downing)

Thanks were extended to Karen and Harriet for their presentation at the last meeting.

Alistair Jeffs confirmed that two of the three sub-groups were set up and were beginning to meet apart from the Lived Experience Sub-Group, which has yet to arrange dates for meeting.

ACTION 2: Dates for the Lived Experience Sub-Group to be arranged and a chairperson installed. (Alistair Jeffs/Oliver Downing)

UPDATES FROM PARTNERS/INDIVIDUALS:

- Alistair confirmed that he had met with colleagues from Wirral at the Autism Hub who informed him of the work they are doing to set up a Partnership Board; they very much want to learn from us and in time we will learn from them. He shared that he is keen to work closely with Wirral in this area.
- Lucy Sumner shared her concerns regarding children who can't attend school and the current education system which isn't as inclusive as it needs to be for young people with SEN. She also expressed her concern regarding the fines being incurred for parents of SEN children for not sending them to school.

ACTION 3: Alistair will speak with lead officers and directors, asking for comments and updates around fines for SEN children who aren't able to attend school.
School fines to be included as an item for discussion at a future meeting. (Alistair Jeffs)

- Update from Health Partners
 - After being asked about the closure of the referral service for people with autism Tom Egerton-Parry responded by saying that in March the CWP took

the regrettable decision to close the waiting list for new referrals due to the high demand for referrals (the CWP are only paid for up to 412 adults per year across Wirral, Cheshire West and Chester, and Cheshire East combined and the waiting list currently stands at about 2,500 referrals). This is not unique to our area; it is a national issue. The CWP felt it wasn't ethical to continue accepting referrals into a service where there is such a long waiting list. He explained that people, via their GP, can exercise their right to choose and ask to be referred to an independent organisation for an assessment. Tom stated that they currently do not have the funding to recruit staff to undertake the volume of assessments that would need to be done based on referrals and are currently trying to identify any potential additional funding to increase assessments that can be done on an annual basis. They are working on a need for stratification appointments which are appointments for people on the waiting list who have a mental health practitioner to look at the impact of undiagnosed autism, identify any other unmet needs, signposting people to online resources or to their local autism hub or other organisations who can offer support whilst people are waiting. Tom continued by informing everyone they are about to roll out the "waiting well" workshops which talk about what autism is, what it isn't, what being referred and going for an assessment is like, what happens if people don't get a diagnosis, and also some practical strategies and information that can help people with the greatest need. Tom wanted to reassure everyone that the Trust is trying to do things to help people who are on the waiting list whilst also working with partners like the ICB to try and identify how they can increase the number of assessments they can do on an annual basis.

ACTION 4: Alistair/Oliver to liaise with Tom Egerton-Parry and Sean Donnelly so they can provide a presentation or briefing on referrals/waiting lists/future assurance and for this to be shared with board members can reflect on it. They will also be asked to speak at the next meeting on the "waiting well" service. (Alistair Jeffs/Oliver Downing)

UPDATES ON CARE QUALITY COMMISSION ASSURANCE AND ENABLING GREAT LIVES STRATEGY:

Emma Cleminson, Adult Social Care Transformation Manager, gave a presentation which included information on the Adult Social Care Enabling Great Lives Strategy (see attached presentation). Emma shared that the Strategy can be reviewed on the Council's website as follows (Ctrl + click to follow link):

[ASC-Strategy-Brochure](#)

[ASC-Strategy-Cheshire-West-and-Chester-Council-Easy-Read](#)

She confirmed that a delivery plan has been established and that the Council have worked with Cheshire Disabled People's Panel to ensure it is fit for publication. She continued that they have just incorporated the comments received from the Cheshire Disabled People's Panel and then the delivery plan will be launched imminently on the Council's website.

Emma then gave a brief overview on the visit of the Care Quality Commission. She explained that they have started a process of inspecting local authorities and how they are discharging their duties under part one of the Care Act; they are inspecting Adult Social Care essentially. She stated that board members may be aware that providers have been inspected for some time but for Adult Social Care we haven't been inspected for over 10 years so this is a new regime that has come into place and will be centred on a framework:

- How we work with people
- How we provide support
- How we ensure safety within the local system
- How we lead our services

Emma confirmed that the Council's self-assessment has been published and is available for those who wish to read it. The link is included in the slides, but she is willing to provide copies if needed.

UPDATES FROM PARTNERS/INDIVIDUALS cont/d.

- Lived Experience

San spoke candidly about her experience growing up and of her experience of the education system. She spoke passionately about not wanting others to go through what she experienced. Gus also shared his school experience too. Alistair commented that the lived experience sub-group will continue to focus on people's experiences.

Discussion then centred on thanking San and Gus for sharing their stories and on how we need to rectify the hurt and harm caused to adults with autism, but equally in getting it right now so our young people do not have to go through these kinds of experience.

- Lale asked if someone from the police could be present at these meetings to discuss what happens when neurodiverse people find themselves in dire needs with the police.

ACTION 5: Alistair to follow up with the Community Safety Team within the Council as they have been doing some work in the area of neurodiverse people and the police – he will see to get some reassurance and updates. (Alistair Jeffs)

ACTION 6: A representative from the police to be asked to join the Partnership Board. (Alistair Jeffs)

SUB-GROUPS:

- Service Mapping

The purpose of the Service Mapping Sub-Group is to capture what is out there in terms of support and to try to map and signpost as appropriate, highlighting any gaps still perceived in this area.

The group has met once and are capturing a lot of information from statutory services and ensuring they are noting key support from these partners.

- Autism/Neurodivergence Strategy

Part of the role of this sub-group is to ensure we are joining everything up as there is a lot of work others are involved in around the children and young people neurodiverse pathway across Cheshire and Merseyside, the adult ADHD pathway and also around autism standards for providers. There is still work outstanding around the autism needs assessment that the Council has a statutory responsibility to develop.

Dorothy shared that there was already an Autism Strategy from the Autism Strategy Group meetings – Alistair confirmed that he would follow up with Dave Biddle to see who was on the original Strategy Group and invite/link in with those as appropriate

ACTION 7: Alistair confirmed that he would follow up with Dave Biddle to see who was on the original Autism Strategy Group and invite/link in with those as appropriate. (Alistair Jeffs)

ACTION 8: Gus to be included in the Strategy Sub-Group mailing list and invites shared to future meetings. (Su Chapelow)

- Lived Experience

This sub-group has yet to meet.

Tom spoke about the “mystery shopper” script he has written. Claire Walley confirmed that she has been working on this in the background and has spoke to the Equality Team asking if there are particular things to “test” which can be brought back to this group using volunteers from the Lived Experience sub-group to use the script to see how it works. If however, anyone has any examples of things/services which can be tested then please contact Claire direct.

ACTION 9: Autism at Reception/Mystery Shopper report from Tom to be included for feedback as appropriate – to be discussed at the Lived Experience sub-group. (Katy Ellison)

ANY OTHER BUSINESS

Medication for ADHD

- Claire Walley asked if anyone was having difficulty accessing ADHD medication. Can you please let Claire know if this is the case so she can feedback to the Director of Public Health.
Sean Donnelly confirmed there is a national shortage of ADHD medication (see link below [Ctrl + click to follow link]):
[Update on ADHD Medication Shortage - NHS Cheshire and Merseyside](#)

Suggestions for Future Agenda Items

- Supported Employment Team be asked to do a presentation at a future Partnership Board to showcase what they are doing in supporting employers understand autism.

Update from the Parent Carer Forum

- Lucy K gave an overview of a project being undertaken called PINS (Positive Inclusion Neurodiversity in Schools). A presentation on this project will be shared at the next Partnership Board. Please see the Focus Group Update and Reasonable Adjustments and Digital Flags Update using the below links (Ctrl + click to follow link):

<https://www.pcfcheshirewest.org/focus-group-update>

What Are Reasonable Adjustments?

ACTION 10: A presentation of the PINS project to be shared at the next Partnership Board. (PINS Project Lead)

ACTIONS:

Number	Action	By
1	Terms of Reference to remain an item for discussion on future agendas	Oliver Downing
2	The following topics be added as future agenda items: parents/guardians of children with autism but who are undiagnosed are fined for non-attendance at school due to mental health/autism; appropriate training for professionals so they have an understanding of autism/neurodivergence; reasonable adjustments	Su Chapelow
3	Alistair will speak with lead officers and directors, asking for comments and updates around fines for SEN children who aren't able to attend school. School fines to be included as an item for discussion at a future meeting.	Alistair Jeffs
4	Alistair/Oliver to liaise with Tom Egerton-Parry and Sean Donnelly so they can provide a presentation or briefing on referrals/waiting lists/future assurance and for this to be shared with board members can reflect on it. They will also be asked to speak at the next meeting on the "waiting well" service.	Alistair Jeffs / Oliver Downing
5	Alistair to follow up with the Community Safety Team within the Council as they have been doing some work in the area of neurodiverse people and the police – he will see to get some reassurance and updates.	Alistair Jeffs
6	A representative from the police to be asked to join the Partnership Board.	Alistair Jeffs

7	Alistair confirmed that he would follow up with Dave Biddle to see who was on the original Autism Strategy Group and invite/link in with those as appropriate.	Alistair Jeffs
8	Gus to be included in the Strategy Sub-Group mailing list and invites shared to future meetings.	Su Chapelow
9	Autism at Reception/Mystery Shopper report from Tom to be included for feedback as appropriate – to be discussed at the Lived Experience sub-group.	Claire Walley / Katy Ellison
10	A presentation of the PINS project to be shared at the next Partnership Board.	PINS Project Lead

DATES OF NEXT PARTNERSHIP BOARD MEETINGS

Wednesday, 8 January 2025
 Wednesday, 5 March 2025
 Wednesday, 7 May 2025
 Wednesday, 2 July 2025
 Wednesday, 3 September 2025

DATES OF NEXT SUB-GROUPS MEETINGS

Autism/Neurodivergence Strategy

Wednesday, 22 January 2025
 Wednesday, 26 February 2025
 Wednesday, 30 April 2025
 Wednesday, 25 June 2025
 Wednesday, 27 August 2025

Lived Experience

Dates to be confirmed

Service Mapping

Friday, 14 February 2025
 Friday, 11 April 2025
 Friday, 13 June 2025
 Friday, 15 August 2025