

NOTES FROM ALL-AGE AUTISM AND NEURODIVERGENCE PARTNERSHIP BOARD

DATED 11 SEPTEMBER 2024

WELCOME AND INTRODUCTIONS:

Alistair Jeffs welcomed everyone to the meeting and introductions were given. He gave Oliver's apologies for not being able to attend today's meeting.

ACTIONS FROM PREVIOUS MEETING:

The action log was discussed and updated. This will be circulated separately but please note the name of the Board will change to **All-Age Autism and Neurodivergence Partnership Board**.

ACTION 1: The title to be changed on the Terms of Reference to All-Age Autism and Neurodivergence Partnership Board. (Oliver Downing)

UPDATES FROM PARTNERS/INDIVIDUALS:

- Divergence Youth Group
 - Karen Flynn and her daughter, Harriet Lockyear-Flynn introduced a new initiative which is aimed at 14–17-year-olds (please see the attached presentation).
 - There was a lot of positive feedback to Karen and Harriet with some comments around having that safe place for teens to be themselves; having a sense of acceptance and the importance of this; Karen/Harriet were asked by another member of the Board to keep an eye on when ostracization/bullying occurs with this age group. Karen said she will, and it will be addressed sensitively.
 - Alistair thanked Karen and Harriet for the presentation and for the work they are doing with this age group in the Chester and Ellesmere Port area. He commented that if they needed help and/or support to let the Board know.
 - Katy Ellison, the Co-production Development Manager for Cheshire West and Chester Council asked how the local authority could help to replicate this around the borough. Karen responded by saying in an ideal world this wouldn't be needed – it's both a society and cultural issue. It just needs others to have the confidence to take up the reins and start a group in their area. It might be helpful to have a proforma for someone to replicate it. The other difficulty is spreading the word about this group. Jackie Goldstraw confirmed that it would be good to share basic risk assessments and forms, which would save on administrative time and, also knowing where suitable community spaces are.

- Update from Health Partners

- Sean Donnelly stated that health partners understand that waiting for a diagnosis can take a long time and that there is only one follow-up appointment post-diagnosis. They acknowledge that support is needed throughout a person's life and so they are working with Dial House asking them to offer support to people throughout their lives. They are hoping to replicate this throughout all of Cheshire.
- Tracy Millington shared that Cheshire and Merseyside are looking at how people are referred for a diagnosis, looking at pathways. They are also working with four schools in each place across Cheshire and Merseyside to create inclusivity in their schools; making it sensory, communicating how to use language, supporting parents – recognising that cultural change is needed.
- Tom Egerton-Parry informed everyone that they are recruiting two full-time outreach and support workers who will be able to help along the journey from pre-diagnosis through to post-diagnosis.
- It was asked if the identification of either a diagnosis or self-diagnosis of girls in schools would form part of the pilot as some have experienced their daughters being “fobbed off” as not having a neurodivergence. It was acknowledged that nationally and locally there is a problem around females being diagnosed due to the masking they do.
- It was mentioned that one of the barriers is you need a diagnosis before you can get support, but you need support to fill the paperwork in to help get a diagnosis – chicken and egg situation. Tom mentioned that having the new roles in place should help with this as they can help with the pre-assessments, help break down some of those barriers.

ADULT SOCIAL CARE CUSTOMER EXPERIENCE SURVEY:

Following a short break, Amy Lavery presented the Adult Social Care Customer Experience Survey (see attached presentation). Amy confirmed that she will be attending some of the Let's Talk events around the borough and will be sharing the survey via this means.

There were some suggestions from the Board:

1. Consider those who try to use Adult Social Care services but can't - ensure the survey doesn't stop people moving on to the next question.
2. Not everyone can read small print.
3. Board members felt it hard to answer questions where they range from “don't agree to strongly agree” and asked if this type of question could be reviewed.
4. It was asked if the answers to the survey will be fed back and form some kind of framework so there is a minimum commitment from every care provider to meet the criteria.

UPDATES FROM PARTNERS/INDIVIDUALS cont/d.

Kath Hingston, Team Manager, Adult Transition Team and Autism Service, Cheshire West and Chester Council, gave an overview of her new team stating that they are working with

young people aged 18-25 years old and will work with young people just before they reach 18 to help prepare them for adulthood. She stated they are keen to be involved with this Partnership Board. Kath shared that they are holding a development day in October and are wanting to find out the issues being faced by young Autistic people. She was keen to give regular updates to the Board as and when she can.

SUB-GROUPS:

Alistair reminded everyone to let Su Chapelow know if they want to be a part of one of the sub-groups. Membership is currently as follows:

Autism/Neurodivergence Strategy

- Paula Spencer
- Karen McGuinness
- Dave Biddle
- Kath Hingston
- Dorothy Jump
- Tony McLinden
- San Cheetham

Lived Experience

- Tom Welsh
- Jo Moss
- Oliver Downing
- Katy Ellison
- Dorothy Jump
- Tony McLinden
- San Cheetham

Service Mapping

- Jo Moss
- Alistair Jeffs
- Claire Walley
- Jackie Goldstraw
- Dorothy Jump

ANY OTHER BUSINESS

Suggestions for Future Agenda Items

- When parents/guardians of children who have autism but are undiagnosed receive school fines for non-attendance when it is due to mental health/autism.
- Social workers need to have an understanding of autism/neurodivergence – proper training for professionals.
- Reasonable adjustments and “mystery shopper” to ensure reasonable adjustments have been undertaken.

ACTION 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)

ACTIONS:

Number	Action	By
1	The title to be changed on the Terms of Reference to All-Age Autism and Neurodivergence Partnership Board.	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

DATE OF NEXT MEETING

Wednesday, 30 October 2024
Wednesday, 8 January 2025
Wednesday, 5 March 2025
Wednesday, 7 May 2025
Wednesday, 2 July 2025
Wednesday, 3 September 2025