Notes from the Autism Norfolk Forum

Held on: Tuesday 01/07/2025 13:00-15:00

Venue: Zoom Meeting

Please note: These notes represent an overview summary of this meeting rather than a verbatim transcript.

NORFOLK AUTISM PARTNERSHIP

Meeting Notes

Agenda Item	Welcome, Introduction & Approval of minutes and action log	Action and Due Date
1.1	Welcome and introductions made. Communication prompts posted to the Zoom Chat window, and their use explained. No reasonable adjustments were requested. Members reported no declaration of interest. Meeting rules where explained	

Agenda Item	Update from the Norfolk Autism Partnership Board	Action and Due Date
2.1	**<u>The New Working Groups</u>** **Diagnosis Working Group** • Monitors and helps improve autism diagnostic services across all age groups in Norfolk • Reviews diagnostic performance data • Addresses service challenges • Co-produces solutions to improve access and reduce waiting times • Ensures autistic voices shape diagnostic pathway developments **Autism Support Pathways Working Group** • Focuses on enhancing and promoting support services for autistic individuals in Norfolk • Manages the Norfolk Autism Directory • Oversees the Autism Partnership Kite Mark • Collaborates with statutory and community organisations to improve service accessibility • Supports autism-friendly practices within communities	

	Young People Autism Advisory Group (YPAAG) • Provides a platform for autistic young people aged 11–18 to share their experiences • Influences decisions affecting autistic young people in Norfolk • Advises the Norfolk Autism Partnership Board • Offers feedback on services and policies • Helps co-design improvements in education, health, and social care	

2.2	**<u>Training Update</u>**
	• Training Delivered:
	  ○ 2 courses delivered since January 2025 to 23 people
	• Upcoming Courses:
	  ○ 5 courses planned for Drug and Alcohol teams
	  ○ 1 course scheduled for a school
	  ○ Discussions ongoing to deliver 3 additional courses
	• Target & Progress:
	  ○ Original 2025 target: 60 participants
	  ○ On track to exceed target with 105 participants expected by end of 2025	

2.3	**<u>Now That's What I Call Autism – Event Summary</u>**
	• Date & Location:
	  ○ Held on 2nd April at The Forum, Norwich
	  ○ Part of Autism Acceptance Week
	  ○ Co-produced with members of the Norfolk Autism Partnership Board
	• Purpose:
	  ○ One-day event celebrating autistic creativity, identity, and community
	• Event Highlights:
	  ○ Makers Market featuring 12 autistic creators
	  ○ 4 autistic performers
	  ○ 3 panel discussions
	  ○ 15 information stands from organisations and charities	

	• Attendance:
	  ○ Approximately 250–300 attendees
	• Online Portal:
	  ○ Event materials and information still available at: https://www.norfolkautismpartnership.org.uk/now-thats-what-i-call-autism-25/	

Agenda Item	Introduction to the new Adult Diagnostic and Support Service	Action and Due Date
3.1	**Update from Oliver Godfrey (ABL Health):** ○ Provided update on mobilisation of new Diagnostic and Navigation service for Norfolk. ○ Recruitment of new team members underway. ○ Offices established in Thetford. ○ Service funded by the NHS and has commenced assessments. ○ On track to deliver at least five assessments per week by July. • NHS Autism Support Services Review: ○ Group discussed concerns regarding green paper's requirement for NHS-employed professionals to conduct diagnoses accepted by the DWP. ○ Current Norfolk support services explained by Oliver: commission covers pre-diagnostic support, assessments, and navigation only. ○ No ongoing support included for anxiety or other mental health needs. ○ Members raised concerns about lack of post-diagnosis support for adults with autism. ○ Highlighted need for additional services and further training for healthcare professionals.	

3.2	**Question:** With the changes coming to the Personal Independence Payment and the possibility of requirement of a NHS diagnosis to access financial support, will the diagnosis provided by ABL Health cover this criteria, as they are not part of the NHS? **Answer:** Unsure, ABL Health will find out the answer to this. The service is commissioned by the NHS (ICB) so it should be.	**Oliver Godfrey** **As soon as possible**

Agenda Item	Update: The Short-Term Autism Support Service	Action and Due Date
4.1	The Norfolk Autism Adult Support Service provides time limited support to Autistic adults and those who are suspected to be autistic. The Support Service has been running for approximately 1 year now and Tracey Walton and Realise Futures provided us with an update.	
4.2	We were reminded about how the Autism Norfolk Forum and the wider membership helped with he co-production of this service: **How the Short-Term Service was co-produced** • **Autism Reference Group:** 5 autistic people co-designing the service, with involvement fees paid by Norfolk County Council • **Autism Friendly Communication Toolkit:** Autism Reference Group co-produced an Autism Friendly Communication Toolkit to support conversations with autistic people	

	• **Face to Face Conversations:** to find out what support autistic people need that could prevent and reduce social care needs
	  ○ Autism Norfolk Forum
	  ○ 8 Library Sessions
	  ○ 23 People
	
	• **Online and Paper Questionnaires:** Autism Reference Group co-produced on online and paper questionnaire based on what people told us
	  ○ 42 Autistic People
	  ○ 32 parent/carers
	  ○ 18 professionals
	  ○ 3 other
	
	• **Choosing the Provider:** Autistic people involved in the choosing the provider who delivers the service
	
	• **Follow up questionnaire:** to name the service, choosing from names suggested by autistic people in the first questionnaire	

4.3	**<u>Year One Review</u>** **Purpose of the Review** • To evaluate what worked well and what didn't during the first year of service. • To identify areas for improvement and inform future development. • Opportunity to reflect and make data-informed changes. **Key Objectives** • Understand the impact of the Norfolk Autism Adult Support Service. • Identify early indicators of success, including: ○ Lessons learned from Year 1.	

	○ Insights to shape Year 2 service delivery and beyond. • Prepare for future research focused on short-term (early help) autism support. **Next Steps** • Commissioners and service leads have developed a draft action plan to implement agreed recommendations.	
4.4	**<u>Did the service receive and accept appropriate referrals?</u>** **Referral Overview** • Total referrals received: 309 (Average: 26 referrals per month) • Most referrals were appropriate, with few rejected. • Some referrals: ○ Came from individuals who did not identify as autistic. ○ Were declined by individuals who felt they did not need the service. **Coaching Uptake** • 112 people (36%) did not receive coaching: ○ 33% did not respond. ○ 8% did not attend the "meet and greet". ○ 46% declined the service. ○ 13% were declined by the service or commissioners (e.g. didn't meet criteria). • 197 people (64%) received coaching. • 43 people used the drop-in service, averaging 0.8 hours per person.	

	Service Response & Improvements **Process changes implemented:** o A detailed conversation at point of referral to clarify: ▪ How the service can support the person. ▪ The specific goal they aim to work toward. **Referrers are reminded:** o Individuals must identify as autistic, as this is an autism-specific coaching service.	
4.5	**<u>Outcomes achieved and reasons for declining the service</u>** **Key Outcome Data** • Just under half of referrals (44%) achieved an outcome from coaching during the reporting timeframe. • Data is based on closure summaries up to end of January 2025. **Reasons for Declining the Service** • Individuals felt they needed longer-term support than the service offered. • Timing issues: too much going on in life, or not the right time to engage. • Belief that coaching was a required step before a Care Act assessment. • Individuals did not believe they needed the service, often because someone else (e.g. a parent) had made the referral.	
4.6	**<u>Outcomes achieved and service declined by referral reason</u>** **Successful Outcomes** • Some individuals achieved multiple types of outcomes, most commonly in:	

	○ Accessing the community ○ Social groups ○ Managing finances ○ Employment and paperwork ○ Building confidence to progress further **No Outcomes were achieved relating to:** ○ Domestic or life skills • Only 3 people achieved outcomes in: ○ Developing routines ○ These were frequently stated goals among those who declined or did not engage Ongoing monitoring of: ○ Lack of/low number of people achieving outcomes related to domestic/life skills and routines ○ High number of people referred for these types of goals who decline or do not respond	
4.7	**<u>Subsequent involvement from adult social care</u>** **Key Statistics** • Most people (64%) did not have any subsequent involvement from ASSD within the time period • 17% (34 people) were referred back by NAASS for consideration of longer-term support.	

	Action Plan • Referrers will be informed that if a person appears to need longer-term care, they should also be referred to a locality team for a Care Act assessment.	
4.8	**Next Steps** • An action plan is in place to implement the findings of the review. • We will continue to develop and monitor the service	

Agenda Item	Break	Action and Due Date
5.1	**A fifteen-minute break was held**	

Agenda Item	Discussion: Reasonable Adjustments required in GP Surgeries	Action and Due Date

6.1	**Reasonable Adjustments required in GP Surgeries**
	As part of our work on the Norfolk All Age Autism Strategy, we're exploring how GP surgeries can make visits easier and more comfortable for autistic people.
	• "Reasonable adjustments" are steps GP surgeries can take to remove barriers caused by communication and information needs.
	• Examples include:
	  ○ Offering longer appointments
	  ○ Providing information in alternative formats
	  ○ Allowing quiet waiting spaces
	  ○ Using clear, direct language during consultations
	We'd like to hear from you:
	• Do you feel you require 'Reasonable Adjustments' to be made when visiting the GP Surgeries are you comfortable requesting these?	

	• What 'Reasonable Adjustments' would help you when visiting the GP Surgery?	
6.2	**Themes from the Discussion** Good things that have happened: • Understanding Staff that take the time to make sure you have everything you need • Suitable waiting areas that are quiet and sensory conscious, i.e. if radio is on it is at a low level, natural light levels. • Adjustments to where you can wait for your appointment. For example, in the carpark with a text message when the GP is ready to see you • The multiple ways to get inContact/book an appointment i.e. over the phone / online • Attitudes of individual staff can make all the difference Things that have not gone well: • The over-reliance on online booking systems even if visiting in person still asked to book an appointment online with little or no support to do so. • Rigid ways of working with little or no flexibility • Not always feeling comfortable to ask for any adjustments due to previous staff attitude or not fully knowing whet the person needs to be supported / what are the options A member talked about a video created by See Me, Hear Me Bedfordshire around Reasonable Adjustments in GP Surgeries. General consensus from the group is that if it more about the individual staff member at the GP Surgery making the changes as opposed to an organisational approach.	

Agenda Item	Any Other Business	Action and Due Date
7.1	**Colour My Words Event.** A member of the Forum told us about an event being held at Little Plumstead Library on the 24th Sept 2:30. This will be a talk on Myers Irlen Syndrome and Visual Stress. This event is free	

Agenda Item	Close of meeting	Action and Due Date
8.1	The NAPB Co-Ordinator thanked everyone for coming along and closed the Meeting	

Future Meeting Dates
• Tuesday 21st October 2025 13:00-15:00