

**Minutes of the
Norfolk All Age Autism Partnership Board (NAPB)**

Held on: Tuesday 16 May 2023, 11:00 – 1:00pm

Venue: Microsoft Teams

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

Name of Attendee	Organisation and or Role
Lee Gibbons	Partnership Coordinator / Note Taker Voluntary Sector Representative, Autism Partnership Coordinator, ASD Helping Hands
Adrian Grant	Co-Chair
Trevor Key	Co-Chair
Stephen Durance	Autistic Adult
Richard Peat	Parent Carer
Alison Furniss	Voluntary Sector Representative Family Voice
Caroline Williams	Head of Communications and Engagement, Healthwatch
Karen Dures	Strategic Business Lead - Autism Adult Social Services (NCC)
Tracey Walton	Autism Commissioning Manager (NCC)
Andy Hudson	Head of Personalisation, Quality of Care for LD and Autism (ICB)
Rebecca Crossley	Children and Young Peoples Senior Clinical Lead Mental Health, Learning disabilities and Autism (NHS Norfolk And Waveney ICB - 26A)
Maria Karretti	Safeguarding Adults Clinical Advisor for Autism and Learning Disabilities
Rachel Gates	Senior Program Manager (ICB)
Joanna Yellon	NHS England (East) locality director
Sharon Brooks	Carers Voice for Norfolk & Waveney
Rebekah Muttitt	Norfolk & Suffolk Foundation Trust, Child & Adult Mental Health Service
Maxine Blocksidge	Senior Adviser SEND (NCC)
Kim Farthing	Social worker (NCC)

Apologies Received	Organisation and or Role
Lorna Bright	Assistant Director of Integrated Operations (Learning Disabilities and Mental Health)
Claire Jones	Local Offer Manager – Family Help and SEND (NCC)
Amanda Johnson	Business Lead – Promoting Independence (Working Age Adults)
James Bullion	Executive Director of Adult Social Services (NCC)
Andrew Macey	Parent/Carer
Catherine Haig	Autism Service Norfolk
Bethany Slaughter	Norfolk Constabulary

Presenters	Organisation and or Role

Agenda Item 1	Pre- Meeting Support	Action and Due Date
1.1	15 minutes was given to pre meeting support for those who required it.	

Agenda Item 2	Welcome, Introduction & Approval of minutes and action log	Action and Due Date
2.1	<p>Welcome and introductions made. Communication prompts posted to the Teams Chat window, and their use explained. No reasonable adjustments were requested. Members reported no declaration of interest.</p> <p>Minutes and action log approved by the Norfolk Autism Partnership Board (NAPB)</p>	
2.2	Action: Arrange for Pathological Demand Avoidance update	Currently on Hold
2.3	Action: Rebecca Crossley to introduce Lee Gibbons to those who can present information on the ratification process and risks	Currently on Hold

Agenda Item 3	Updates on the Diagnostic waiting times	Action and Due Date
3.1	Tracey Walton gave us an update on the diagnostic waiting times for Norfolk	
3.2	<p>Adult wait times</p> <p>In the past 12 months there have been 9971 referrals into the service.</p>	

	<p>With monthly average of 81. In March 2023 there were 120 referrals.</p> <p>In March 2023 there 559 adults waiting for an assessment (24% decrease since last reporting)</p> <p>Over the past 12 months there have been:</p> <ul style="list-style-type: none"> • 1141 completed assessments. <ul style="list-style-type: none"> ○ 186 by autism Service Norfolk ○ 955 by independent <p>The data reported, at the end of March 2023. Last reported Jan 2023</p>	
3.3	<p>Waiting times for first appointment:</p> <ul style="list-style-type: none"> • 3 waiting over 200 weeks. • 51 waiting between 104-200 weeks. • 140 waiting between 52 and 104 weeks. • 165 waiting between 18-52 weeks. • 200 waiting under 18 weeks <p>It was noted that those waiting over 200 weeks was not a true reflection due to how the services measures waiting times for those that disengage then reengage</p>	
3.4	<p>Question: Is there any data around referrals due to patient choice?</p> <p>Answer: There is currently no data for this but an action point will be taken away to see if this data can be collated.</p>	Tracey Walton
3.5	<p>RM mentioned that Rebecca Humane was involved in a working group around patient choice that could feed into the Norfolk Autism Partnership.</p>	
3.6	<p>RC mentioned that the 'Top Tips' was nearly ready for circulation. This guide provides people who are seeking a private diagnosis to understand what an assessment would entitle and how to make sure this is NICE compliment.</p>	
3.7	<p>Concerned members raised that it was mentioned that the current rate of referrals to completed assessments was not sustainable and that things are likely to get a lot worse. Autism Service Norfolk (ASN) would be unable to meet demand. Could the NAPB help to increase funding to this service?</p>	
3.8	<p>JY said that there had been increased investment into the funding of care services through the waiting list initiative fund and the service development fund set</p>	

	for 2023/2024. They also commented that we need to look at how efficiently the money was being spent and to make service robust and sustainable enough.	
3.9	LG informed the group that a letter had been sent to the chair of the Norfolk and Waveney ICB from ASD helping Hands, with concerns around the waiting list initiative with inability to call off additional contracts with external provider that will result in increased waits. The letter called for an increase of funding for these services. JY said that these letters had been received and we should expect a response from the chair soon.	
3.10	AG asked the partnerships what they wanted to do regarding the waiting times in adult diagnosis. Some suggestions where: -To publish a statement on the NABP website regarding waiting times for an adult diagnosis. -Refer this matter to the diagnosis working group, who are reviewing the Portsmouth Model	
3.11	There was some concerns around making a public statement regarding diagnosis. With some members saying hey would have to abstain from the vote due to conflict of interests. JY commented that careful consideration would need to be taken with the wording of any statement as the partnership should be working collaboratively to solve any issues that arise.	
3.12	Mentions of support available to help during the waiting period for a diagnosis where given: -Living well with Autism Course (Recovery College) -Educations Psychologist and Specialist Support Team -Just one Norfolk website Action: LG requested to be sent information on services to add to the Norfolk Autism Partnership Board website	Board Members (Ongoing)
3.13	Question: RP asked if we knew where Norfolk stood in the national standing of Autism diagnosis. Were we performing better or worse than other areas in the country?	

	Answer: TW mentioned that nationally services are struggling with the management and waiting times for ASD / ADHD diagnosis, she also acknowledged that without fundamentally changing it will cause issues but that this is a national concerns and not just confined to Norfolk.	
3.14	Action: JY will try to get the national position for Autism Diagnosis	
3.15	JY informed the partnership that she had been instructed by the Quality and Safety committee to do a deep dive on autism assessments and is due to present to the ICB Executive Management team.	
3.16	The group were asked again whether that wanted to put a statement together regarding Adult diagnostic waiting times. Many members said that they would have to consult with their higher management teams and would not be able to be included in the vote. These members where: Rachel Gates / Maxine Blocksidge / Tracey Walton / Rebecca Crossley AF commented in the chat that any statement needed to be backed by a plan of action.	
3.17	Action: To organise a Task and Finish group to put together a statement regarding the Adult wait times for a diagnosis in Norfolk to be published on the Norfolk Autism Partnership Board Website.	Lee Gibbons (By next board meeting)
3.18	Children and Young People wait times. Norfolk Community and Health Trust (central and West) <ul style="list-style-type: none"> • 5146 children on the waiting list as of April 2023 • 70% are awaiting review (they have had at least one contact and awaiting further assessment) • Of those in active review, 36% have been on the pathway for 1-2 years, 40% 2+years. James Paget Hospital <ul style="list-style-type: none"> • 1770 referred into service between April 2022 and April 2023 • 497 Awaiting assessment. • 977 awaiting initial appointment (average 16 week wait) • 148 people added to waits each month 	

3.19	Waiting list initiative set to go live shortly with referrals from NCHC and James Paget moving to private providers.	
3.20	<p>Question: TK asked for confirmation on when the external contracts for adult diagnosis finished.</p> <p>Answer: There are still 20 outstanding assessments to be completed, no more referrals to be passed. The funding for this project concluded March 2023.</p>	

Agenda Item 4	Break	Action and Due Date
4.1	A 15-minute break was held	

Agenda Item 5	Forward Working Group Update	Action and Due Date
5.1	<p>LG provided an update on the Forward Working group.</p> <p>Changes have been made to the Terms of reference and Roles and Responsibilities documents to reflect the introduction of a steering group.</p>	
5.2	<p>These changes were approved by the Partnership pending changes to:</p> <ul style="list-style-type: none"> • Change of glossary terms ICB to replace CCG. • Minor Typos to be corrected. • Adjustment to the Roles and responsibilities section 3.0 	
5.3	<p>The Forward Working group now needs to form the Steering group.</p> <p>Action: LG to send out Expressions of interest to Autistic members who may want to participate in the steering group.</p> <p>AG and TK have expressed interest to join the steering Group.</p>	<p>Lee Gibbons 19/05/2023</p>
5.4	<p>Action: Norfolk Autism Partnership Board website to be updated with information on the steering group and news terms of reference and roles and responsibilities document.</p>	<p>Lee Gibbons 19/05/2023</p>

Agenda Item 6	Norfolk Autism Forum Update	Action and Due Date
6.1	<p>LG provided an update on the Norfolk Autism Forum that was held on the 22 March 2023. The Theme of this forum was Advocacy.</p> <p>There were two guest speakers one from Statutory service and an independent provider.</p>	
6.2	<p>The three main themes that came out of the discussion where:</p> <ul style="list-style-type: none"> • Post diagnostic advocacy support for Adults and Parents/Carers • The group felt that there was not enough community Advocacy Services • Advocacy services need to be able to communicate with people in different ways and be able to change how they communicate with someone based on their needs. <p>This feedback has gone directly back to the services that presented during the forum.</p>	
6.3	The next forum will be themed around mental health as requested by an attendee at the Forum	
6.4	The next forum is provisionally planned for Tuesday 11 July 2023.	

Agenda Item 7	Any Other Business	Action and Due Date.
7.1	<p>Representation on the Learning Disabilities and Autism Boards</p> <p>LG informed the Board that the LD & A Boards are now ready to have Autistic people present at the Board and have developed a draft terms of reference that they would like to Partnership to have input in.</p> <p>Rebecca Crossley also asked to be included in this meeting.</p> <p>Action: LG to liaise with RC to arrange a meeting between themselves and the co-chairs to look over the draft terms of reference.</p>	<p>Lee Gibbons / Rachel Crossley/ Rachel Gates</p>
7.2	<p>Coalition for change invite and involvement</p> <p>LG informed the partnership that the Coalition for change had been in contact with partnership and wished to meet to discuss how we could work together.</p> <p>Action: Lee Gibbons to follow up and arrange</p>	<p>Lee Gibbons</p>

7.3	<p>Use of Easy Read</p> <p>One of the Autistic members of the board has questioned our use of easy read as a default communication method for the board. They felt that this was catered more towards those with a Learning Disability as opposed to Autism.</p> <p>Members of the board said that information needed to be presented in multiple formats to be accessible.</p> <p>Question: Do we present the board PowerPoint in full or via easy read?</p> <p>Answer: After discussion it was agreed to work in co-production with our Autistic members to produce the next slide deck for the Partnership as a trial to see if this improves things.</p> <p>Action: To coproduce next slide deck with Autistic members</p>	Lee Gibbons
7.4	<p>Use of ASC opposed to ASD</p> <p>During the Norfolk Autism Forum, an attendee asked the Norfolk Autism Partnership to consider moving from Autism Spectrum Disorder (ASD) to Autism Spectrum Condition (ASC).</p> <p>The pros of this would be moving away from the medical model and may make the partnership more inclusive.</p> <p>Cons of this would be the need to change our training packages, confusion with the changing of terms and statutory services using the ASD abbreviation as this is how it appears in documents and the DSMI-V (Diagnostic manual)</p> <p>Agreement from Board: The Board agreed to continue to use the term ASD, however if someone's preference is to use the ASC abbreviation then this will be done when discussing items with them personally.</p>	
7.5	<p>Draft Communication Toolkit</p> <p>TW and KD have worked on a coproduced Autism Friendly communication toolkit. The Board asked to approve this and allow the use of the Norfolk Autism Partnership Logo on the document.</p> <p>Agreement from the Board: The board agreed to the use of the Logo on this document</p>	
7.6	<p>MB informed the group that the SEND Survey was now live and asked partners to promote this within their own organisations and communication channels</p>	

7.7	It was noted that the following weeks are coming up : <ul style="list-style-type: none"> • Carers week commencing 5th June 2023 • Co-Production Week 3rd July 2023 	
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Agenda Item 8	Close of Meeting	Action and Due Date.
8.1	The Co-chairs closed the official meeting	

Agenda Item 9	Post Meeting Support	Action and Due Date.
9.1	30 Minutes was provided at the end of the meeting as a reasonable adjustments and to provide support to those who attended the meeting.	

Date, time and location of next meeting
Tuesday 18 July 2023 11:00-13:00 (Microsoft Teams)

Glossary

ANF:	Autism Norfolk Forum
ASD:	Autism Spectrum Disorder
CQC:	Care Quality Commission
ICB:	Integrated Care Board
FOI:	Freedom of Information
GDPR:	General Data Protection Regulations
ICB:	Integrated Care Board
LDP:	Learning Disability Partnership
LDPB:	Learning Disability Partnership Board
NAP:	Norfolk Autism Partnership
NAPB:	Norfolk Autism Partnership Board
NAS:	National Autistic Society
NCC:	Norfolk County Council
NCH&C:	Norfolk Community Health and Care
N&SFT:	Norfolk and Suffolk Foundation Trust
SEND:	Special Educational Need and Disabilities
UEA:	University of East Anglia
WAW:	World Autism Week
WG Lead:	Working Group Lead