



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

**Held on: Tuesday 21<sup>st</sup> November 2023, 11:00 – 1:00pm**

**Venue: Microsoft Teams**

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

<b>Name of Attendee</b>	<b>Organisation and or Role</b>
Lee Gibbons	Partnership Coordinator / Note Taker Voluntary Sector Representative, Autism Partnership Coordinator, ASD Helping Hands
Adrian Grant	Co-Chair / Autistic Adult
Caron Ager	Commissioning Programme Manager Learning Disabilities and Autism (ICB)
Alison Furniss	Family Voice
Caroline Williams	Head of Engagement – Health Watch Norfolk
Claire Jones	Local Offer Manager - SEND Strategic Improvement and Partnerships (on behalf of Maxine Blocksidge)
Holly Purchase	Autistic Adult
Andy Hudson	Head of Personalisation, Quality of Care for LD and Autism
Joseph Jarvis	Autistic Adult
Karen Dures	Strategic Business Lead – Autism (NCC)
Tracey Walton	Autism Commissioning Manager (NCC)
Maria Karretti	Safeguarding Adults Clinical Advisor for Autism and Learning Disabilities
Laura Edwards	Autistic Adult
Lucy Adcock	Norfolk Learning Disability Co-ordinator
Richard Peat	Parent/Carer
Sharon Brooks	Chief Executive – Carers Voice
Bethany Slaughter	Norfolk Police Mental Health Team Supervisor
Stephen Durrance	Autistic Adult
Susan Ackley	Senior Educational Psychologist & Autism Education Trust Hub Lead Trainer for Schools

<b>Apologies Received</b>	<b>Organisation and or Role</b>
Trevor Key	Co-Chair
Catherine Haig	Clinical Psychologist (Autism Service Norfolk)
Tina Allen	Support Worker (Autism Service Norfolk)
Maxine Blocksidge	Senior SEND Advisor

Rachel Gates	Senior Programme Manager (Norfolk County Council)
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Presenters	Organisation and or Role
Tracey Jones	Coalition for Change Co-ordinator

Guests	Organisation and or Role
Rose Blackthorn	Rethink
Pippa Belderson	Researcher (University of East Anglia)

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

Agenda Item	Welcome, Introduction & Approval of minutes and action log	Action and Due Date
1.1	Board Members were asked to introduce themselves in the Teams chat function	
1.2	<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> <p>Code of Conduct to be monitored by Lee Gibbons</p>	
1.3	<p><b>Action:</b> Arrange for Pathological Demand Avoidance update</p> <p>Agreed to sit with the diagnostic Working Group. Board to monitor/</p>	
1.4	<p><b>Action:</b> Add information of Autism relevant organisations to the partnership's independent website</p> <p>On hold until the Refreshed strategy is agreed.</p>	
1.5	<p><b>Action:</b> Rachel Gates to feedback to the NAPB on the request for Autistic people to join the LD&amp; A partnership Board.</p> <p>In progress updated expected after the publication of the Tricordant consultation.</p>	
1.6	<p><b>Action:</b> To keep in contact with Tracey Wooldridge regarding further updates to the Care, Education and treatment review (to be expected in the early 2024)</p> <p>Kept on hold until early 2024.</p>	

Agenda Item 2	Oversight Board Update	Action and Due Date
2.1	The oversight board continues to work on their live priority document.	
2.2	No meeting was held in December 2023 to allow members to focus on the live priority document	
2.3	Expect to present to the Autism Partnership Board early 2024.	

Agenda Item 3	Diagnostic Update (Diagnostic Data circulated before the meeting)	Action and Due Date
4.1	<p><b>Adult Diagnosis (without a Learning Disability)</b></p> <ul style="list-style-type: none"> <li>• Annual average referrals of 88 each month</li> <li>• Total number of adults waiting 829 (48% increase since completion of the initiative work completed)</li> </ul> <p>Waiting period breakdown:</p> <ul style="list-style-type: none"> <li>• 17 waiting between 200-104 weeks (2 person waiting longer than 200wks)</li> <li>• 175 waiting between 104–52 weeks</li> <li>• 421 waiting between 52-18 weeks</li> <li>• 216 waiting up to 18 weeks</li> </ul>	
3.2	<p>With the waiting list initiative work ended, continued high referral rates and low assessment outcomes has resulted in a 48% increase in people waiting a diagnosis.</p> <p>Those 17 people waiting between 104 and 200 weeks in July 2023, is the lowest reported. 386 people were waiting in December 2021 that means a percentage reduction of 95%.</p> <p>Commissioners continue to work with the NAP diagnosis working group to re-engineer adult autism diagnostic pathways and in line with procurement regulations to recommission the service from October 2024.</p>	

3.3	<p><b>Children and Young People wait times.</b></p> <p><b>Norfolk Community and Health Trust (central and West)</b></p> <p><b>As of Nov 2023</b></p> <ul style="list-style-type: none"> <li>• 5954 children on the waiting list</li> <li>• Average of 260 referrals a month</li> </ul> <p>Data for waiting was not available for meeting.</p> <p><b>James Paget Hospital</b></p> <ul style="list-style-type: none"> <li>• 1435 children on the waiting list</li> <li>• Average of 99 referrals a month</li> </ul> <p>Data for waiting was not available for meeting.</p> <p><i>Intelligence indicates, of those referred at 16 plus 80% are referred for an autism assessment.</i></p>	
3.4	<p>NDD Commissioning and Clinical Project group in place for those referred at 14 plus who may transfer to adult pathways to ensure children and young people and adults waiting are not adversely impacted.</p>	
3.5	<p><b>Question: Is there likely to be an increase in assessment rates?</b></p> <p>Throughput of assessments was increased last month, and additional pots of funding are being looked at to try to increase the rate of assessments.</p> <p>There is no timeline for this application and award of these funding streams.</p>	
3.6	<p><b>Question: Has Patient Choice / Right to Choose had a positive impact on the waiting lists?</b></p> <p>This question will be taken to the ICB to see if this has had an impact.</p> <p>There are still worries that GPs and Health Practitioners are not informing patients about their right to choose and these streams. We need to look at how this information is disseminated to not only patients but also GPs and Health Practitioners.</p>	
3.7	<p><b>Question: Does the Adult waiting list numbers also reflect the amount of young people that are transferred to this service?</b></p> <p>Not currently as no transfers have taken place</p>	

3.8	<p><b>Question: Is there any data around the number of assessments carried out for children and young people?</b></p> <p>This data is not provided as there is no obligation to record it and to acquire it would be a manual process.</p> <p><b>Action: Suggestion of a meeting with commissioners of Children and Young People diagnostic services (Clare Angel) to find out these assessment numbers.</b></p> <p><i>Need to be clear on what numbers we are asking for i.e., amount of ASD assessments completed or those who have been given a decision following their assessments.</i></p>	Lee Gibbons & Co-Chairs
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Agenda Item 4	Update from the Autism Strategy Reference Group	Action and Due Date
4.1	<p>This group involves:</p> <ul style="list-style-type: none"> <li>• 2 autistic adults</li> <li>• 2 Norfolk Conty Council reps</li> <li>• NAPB rep</li> </ul>	
4.2	<p>This group's purpose is to work together to:</p> <ul style="list-style-type: none"> <li>• design and test autism friendly communication tools</li> <li>• support autism friendly conversations</li> <li>• reach autistic people and their parents and carers</li> </ul> <p>to deliver the refreshed Norfolk All Age Autism Strategy.</p>	
4.3	<p>Achievements to date:</p> <ul style="list-style-type: none"> <li>• Created an online document in plain English and easy read as well as an animation for the looking back / looking forward communications.</li> <li>• Designed and tested a questionnaire and workbook to find out what is important to autistic people.</li> <li>• Designed and implemented a communication plan to distribute the workbook and questionnaire</li> </ul>	

4.4	<p>Engagement for the online questionnaire:</p> <p><b>Email Campaign</b></p> <p>Email sent: 605 (open rate of 50%)</p> <p>Links within emails clicked -11% (a good rate is 2-5%)</p> <p><b>Social media</b></p> <p>Viewed posts:4069.</p> <p>Reactions, likes, comments:105.</p> <p>Shared:43</p> <p><b>Completed questionnaires and workbooks: 137</b></p>	
4.5	<p>The Autism Strategy Reference group will now:</p> <ul style="list-style-type: none"> <li>Analyse the data from these questionnaires and workbooks.</li> <li>Organise a facilitate library and in person sessions to sense check the information gained.</li> </ul>	
4.6	<p>The Autism Strategy Reference group is continuing to ask people who wish to join to contact the Partnership Board at <a href="mailto:contact@norfolkautismpartnership.org.uk">contact@norfolkautismpartnership.org.uk</a>.</p>	
4.7	<p>Sharon Brooks (Carers Voice) has offered to engage the voice of Carers in the Norfolk All Age strategy refresh</p>	
4.8	<p><b>Question: Have Mental Health Commissioners been involved in the strategy refresh?</b></p> <p>They have been contacted and encouraged to complete the questionnaire/workbook.</p> <p>The strategy will ask partners how they are going to achieve the priorities set out in the refreshed all age autism strategy.</p>	

Agenda Item 5	Update on the Short-term service research project	Action and Due Date
5.1	Norfolk County Council have been awarded funding from the ICB to carry out a research project into the Norfolk Autism Adult Support Service to be delivered by Realise Futures.	
5.2	This project will run from 23 October 2023 -31 March 2024	
5.3	<p>The aim of the research project is to:</p> <ul style="list-style-type: none"> <li>Identify the most appropriate tools for measuring autistic adult's wellbeing.</li> <li>These can be used to evaluate the service</li> </ul>	

	<ul style="list-style-type: none"> <li>• These will also inform the bid for longer term research funding.</li> </ul>	
5.4	<p>Research Advisory Group and Project Team will work together to:</p> <ul style="list-style-type: none"> <li>• Design and test an autism friendly online questionnaire.</li> <li>• Inform how to effectively engage with autistic people.</li> <li>• Evaluate the responses.</li> <li>• Inform best way to report back to autistic people.</li> </ul>	
5.5	<p>This project will be overseen by the Autism Research Advisory Group.</p> <ul style="list-style-type: none"> <li>• 5 autistic people have joined the group.</li> <li>• 14 other people expressed an interest – places were offered on first come, first served basis.</li> <li>• We have contacted all those who were not successful – option to be kept informed of other ways to get involved.</li> <li>• Meetings will take place via Microsoft Teams, once a month until the end March 2024.</li> <li>• First meeting is on 29 November.</li> <li>• The group will be facilitated by Pippa Belderson, Tracey Walton and Karen Dures.</li> </ul>	
5.6	<p>The project team for this project will be :</p> <ul style="list-style-type: none"> <li>• Dr Pippa Belderson – researcher from UEA.</li> <li>• Tracey Walton and Karen Dures – from Norfolk County Council.</li> <li>• Dr Sarah Hanson and Dr Birgit Larrson – from UEA.</li> </ul>	
5.7	<p><b>Question: What are the longer term aims or desired outcome of the short-term research project?</b></p> <p>To gather evidence to look at putting in for funding for a longer-term research project and a plan for this.</p> <p>To look at how effective this service is and to help develop services locally and nationally.</p>	

5.8	<b>Question: How is someone's wellbeing being scored?</b> Through a mixture of qualitative and quantitative data collection methods. This will cover someone's global quality of life.	
5.9	<b>Question: How can the Norfolk Autism Partnership support this project?</b> No current actions for the Norfolk Autism Partnership but this can be explored further	
5.10	Brief update in January of 2024 has been requested by this may need to be postponed. To be discussed with the advisory group.	

<b>Agenda Item 6</b>	<b>Break</b>	<b>Action and Due Date.</b>
6.1	A 10-minute break was held	

<b>Agenda Item 7</b>	<b>Coalition For Change</b>	<b>Action and Due Date.</b>
7.1	As a result of an action from our previous meeting (Sept 2023) Tracey Jones joined to talk through their invite and provide further information on the Coalition for Change	
7.2	Coalition for Change was set created alongside the SAR review after the incidents of Cawston Park in 2021.  It has been set up to embed the 'Homes not Hospitals, into services and commissioning both in Norfolk and Nationally.	
7.3	Coalition for Change is comprised of: <ul style="list-style-type: none"> <li>• Challenging Behaviour Foundation</li> <li>• Joan Maughan</li> <li>• Margaret Flynn</li> <li>• Keith and Jean Bailey</li> <li>• Independence Matters</li> <li>• Dame Philippa Russell DBE</li> <li>• Integrated Care Board (Young Person Lead)</li> <li>• Jerome Mayhew MP</li> </ul>	



7.4	<p>Why should the Norfolk Autism Partnership join the coalition for change?</p> <p>We believe that as a collective we will be stronger if we work together.</p> <p>We would contact you whenever we wanted to collectively lobby / campaign / challenge or support service standards or seek legal change – both in Norfolk and nationally.</p> <p>We would check with you on each campaign or challenge to ensure that you retain full control over how and where the Partnership’s information is used. There is no subscription or fee for membership.</p> <p>Any individual organisation within the Partnership is welcome to join on their own.</p>	
7.5	<p>The Coalition for Change waiting to hear whether we will be funded by Norfolk County Council and the Integrated Care Board for 2024. They are hoping for a decision by December 2023.</p>	
7.6	<p>These are the further things that the Coalition for Change have planned.</p> <ul style="list-style-type: none"> <li>• Continue to encourage partnerships and organisations to join the Coalition, so we can have a collective influencing power.</li> <li>• Build on relationships with the Pathway into Adulthood teams and the Integrated Care Board young peoples’ teams to ensure that children and young people are included in service design and change. We want the voice of young people and families in transition to join us.</li> <li>• Continue to champion “Homes not Hospitals” as a core principle for LD and A service strategies and commissioning.</li> <li>• Continue to be part of the stakeholder group for NHS England on their complex care system re-design.</li> <li>• Share national best practice with Norfolk based organisations and groups and showcase Norfolk best practice.</li> <li>• Challenge organisations to ensure the voices of individuals with learning disabilities and/or autism with behaviours that challenge are planned into any co-production work or project in Norfolk.</li> </ul>	

7.7	<b>Action: The Norfolk Autism Partnership Board have been asked if they would like to join the Coalition for Change as an Organisation. A poll to be sent out to all members to vote on this.</b>	Lee Gibbons
7.8	After the events of Cawston park Healthwatch used their power of 'Enter and View.' There is a report available on their website regarding Cawston Park	
7.9	<p><b>Question: How does an organisation come into contact with and invited to join the Coalition?</b></p> <p>All organisations are part of the Coalition on a voluntary basis. It was previously made up of a group of people and organisations but lacked the time to progress.</p> <p>While recruitment for the Coalition has been happening, this has not been a productive use of people's time due to the Coalition still trying to find it's feet.</p> <p>The Coalition for Change is interested in having self-advocates join the coalition especially those who have experience of 'Locked Provision.'</p>	
7.10	<p><b>Question: Does the Coalition for Change focus on a range of care provision and not just 'locked provision'?</b></p> <p>The Coalition for Change started looking at 'locked provisions' although Tricordant have asked the involvement of the Coalition in the development of care strategies.</p>	
7.11	<b>Action: To send Autistic members interested in joining as individuals Tracey Jones's email address.</b>	Lee Gibbons

<b>Agenda Item 8</b>	<b>Reference guides for families Norfolk / Waveney and Autism and Mental Health Briefing</b>	<b>Action and Due Date.</b>
8.1	Maria Karretti has co-produced a reference guide for Families and Children living in Norfolk and Waveney on support services that they are able to access and that professionals can sign post to.	
8.2	<p>These need to be shared as far as possible some possible places to share to are:</p> <ul style="list-style-type: none"> <li>• GP Practices</li> <li>• Just One Norfolk</li> <li>• Computer systems of Health care settings</li> <li>• School's</li> </ul> <p>To also at making paper copies to be shared alongside electronic.</p>	

8.3	<b>Action: These will be made available on the Norfolk Autism Partnership's website and circulated to members.</b>	Lee Gibbons
8.4	<p><b>Questions: Will one be produced for Adults (25+)?</b></p> <p>No Adult resource planned however some on the links on this reference guide are also relevant to adults. This may prove useful for GPs to have as reference when working with adults.</p> <p>The Diagnostic and Support Working group are going to look at putting something similar together for adults.</p>	
8.4	<p>Maria Karretti also presented the 7-minute briefing for Autism and Mental Health.</p> <p>This was positively received by the Norfolk Autism partnership board.</p> <p>There was some feedback on the quote and working used which has now been corrected.</p>	
8.4	<b>Action: To make available on the Norfolk Autism Partnership Board website</b>	Lee Gibbons

<b>Agenda Item 9</b>	<b>Any Other Business</b>	<b>Action and Due Date.</b>
9.1	<p>The Norfolk Autism Partnership has been contacted regarding work experience placements for an Autistic student. Anything suitable to be sent to Lee Gibbons, who can they relay information back.</p> <p><b>Action: Find out students interests to help with finding suitable placement</b></p> <p>Also, a suggestion to contact the Local employment service to see if they had any ideas or suggestions.</p>	Lee Gibbons

<b>Agenda Item 10</b>	<b>Close of Meeting</b>	<b>Action and Due Date.</b>
10.1	The co-chair provided the date of the next meeting and closed the meeting.	

<b>Date, time and location of next meeting</b>
Tuesday 30 January 2024 11:00-13:00 (Microsoft Teams)
<b>Upcoming Meeting Dates</b>

Tuesday 26 March 2024  
Tuesday 28 May 2024  
Tuesday 30 July 2024  
Tuesday 24 September 2024  
Tuesday 26 November 2024  
Tuesday 28 January 2025  
Tuesday 25 March 2025  
Tuesday 27 May 2025  
Tuesday 29 July 2025  
Tuesday 30 September 2025

## 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
LD & A Board	Learning Disability and Autism Programme 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
NSFT	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