



**Notes of the Autism Norfolk Forum (ANF) Meeting  
Held on: Wednesday 12 February 2020, 17:00 – 20:00**

**Venue: Aylsham Town Hall, Town Hall, Market Place, Aylsham, NR11 6EL**

**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	NAPB member and Engagement Working Group Lead (ASD Helping Hands)
Tracey Walton	NAPB member and Autism Commissioning Manager - Norfolk County Council (NCC).
Stephen Durrance	Norfolk Autism Partnership Board (NAPB) member
Gemma	ASD Helping Hands
Dr Catherine Haig	NAPB members and Autism Service Norfolk
Autism Administrator	Note Taker (NCC)
Members of the public	10

<b>Agenda Item 1</b>	<b>Welcome and Introduction</b>	<b>Action and Due Date</b>
1.1	<p>Welcome and introductions made. Communication cards distributed, and their use explained. Directions to quiet rooms were given. Fire exits and alarm procedures outlined.</p> <p>Recording of meeting requested as a reasonable adjustment, that was declined due to individuals sharing their personal health experiences and lack of assurance regarding alignment to GDPR.</p> <p>Acknowledged a note taker is provided.</p> <p>NAPB Code of Conduct introduced and explained. Gemma (ASD helping hands) nominated as Code of Conduct monitor.</p> <p><b>Noted:</b> Change to agenda to rearrange the order of items but not the content. This was accepted.</p>	

Agenda Item2	Update from the Board with Tracey Walton	Action and Due Date
2.1	<p><b>Autistic Co-Chair</b></p> <p>Autistic/parent-carer Board members submitted expressions of interest for the vacant NAPB Autistic Co-Chair position. Trevor Key obtained support from autistic/parent-carers and voluntary organisations Board members at a coproduction event held on the 22 Jan 2020. He then obtained full support from all Board members at the NAPB held on the 29 Jan 2020.</p> <p>A member of the public asked if Board members are voted onto the board. Tracey Walton advised that the Board offers membership, to be more inclusive and enable people to get involved in ways and times that suit them. As positions become available, or at a review all applications are considered, and volunteering opportunities offered aligned to the working group or Boards priority work.</p> <p><b>Noted:</b> The NAPB membership process was shared with no objection or concerns raised.</p>	
2.2	<p><b>Diagnosis Working Group update:</b></p> <p>The Diagnosis Working Group continues to monitor the ongoing progress of both adult and child diagnosis and support services. Membership of the working group is being reviewed to emphasise coproduction and improve the way information is fed to the Board, commissioners, providers and wider networks.</p>	
2.3	<p><b>Engagement Working Group update:</b></p> <p>The Board on the 29 Jan 2020 approved the launch of the local Autism Strategy during World Autism Week at an event in King's Lynn. The adult autism questionnaire and promoting partnership membership will be communicated at the same time. Autistic people in receipt of social care and where appropriate their parent/carers will be written to. Attendees were asked to promote the event widely.</p> <p>The Board held on the 29 Jan 2020 approved forms produced by the working group, subject to continuous improvement and feedback from today's Autism Norfolk Forum.</p> <p>On the 29 Jan 2020, the Board approved an approach to manage data compliance, Freedom of Information and a complaints process. The Board delegated final approval to the Engagement working group.</p>	

2.4	<b>Noted:</b> The NAPB works with a wide range of partners to influence commissioners within the CCGs and NCC. It is a partnership and does not have the same legal responsibilities as statutory bodies.	
2.5	<p><b>Workforce Development Working Group update:</b></p> <p>The Workforce Development working group is updating NCC autism training to be in line with new Core Capabilities Framework for Supporting Autistic People (2019). This includes updates for general eLearning and specialist in-person training, as well as improvements to be more user-friendly and accessible. Training is being rolled out across NCC and is also being undertaken by Senior Leadership Team. Feedback is reported as overwhelmingly positive. Ambition is to spread training as widely as possible.</p> <p>Member of the public advised challenges regarding autism awareness during assessments. Acknowledge the training will need time to embed into practice with a need to continually monitor impact. Advised autism champions are being identified to support this process. Member of the public advised schools need autism training. Advised autism training is being rolled out to schools but this is separate to the autism training coproduced by the NAPB.</p>	
2.6	<b>Noted:</b> Important that schools and agencies employed to work in schools (e.g. Norse) are autism trained. Importance of identifying autistic traits in girls emphasised. Suggestion that autistic people who have completed mainstream school act as advisors/mentors/buddies.	
2.7	<b>Noted:</b> Setting up “Autism Friends” groups on similar lines to “Dementia Friends” groups that are suggested as helpful. Key workers in different settings with autism training considered helpful.	
2.8	<b>Agreed:</b> Suggestions to include more experts by experience / advocacy groups in mentoring roles will be brought to the attention of the Board.	Engagement Working Group
2.9	<b>Agreed:</b> Ways to raise autism awareness and training on a national level will be brought to the attention of the Board.	Engagement Working Group
2.10	<p><b>Data Working Group update:</b></p> <p>To enable the Board to grasp and measure progress quickly and easily, the data working group is looking to design and implement an autism dashboard. On the 22<sup>nd</sup> January, at a coproduction event that involved autistic and parent/carers Board members and</p>	

	voluntary organisation they started to look at priority 1 and 3.  The Board approved the approach and asked for a plan to be put in place to deliver an autism dashboard.	
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Agenda Item 3	Focus group to obtain feedback on the Norfolk Autism Partnership documents with Tracey Walton	Action and Due Date
3.1	<b>Agreed:</b> The Autism Norfolk Forum agreed with the Boards feedback on the Code of Conduct and recommended the following alterations for the Engagement Working Groups consideration: <ul style="list-style-type: none"> <li>• Change to “red card” illustration</li> </ul>	
3.2	<b>Agreed:</b> Partnership Membership process agreed, subject to following alterations for the Engagement Working Groups consideration: <ul style="list-style-type: none"> <li>• Changes to colour scheme so remains clear and readable when printed in black and white.</li> <li>• Re-check for readability and ease of understanding.</li> </ul>	
3.3	<b>Agreed:</b> Consent form agreed.	
3.4	<b>Agreed:</b> Application form agreed.	
3.5	Complaint process discussed in more detail following questions from attendees. Lee Gibbons and Tracey Walton explained how members of the Engagement Working Group are appointed, the aim of appointing members with a broad range of applicable skills and viewpoints, and the difficulties involved in previous methods of membership.  <b>Agreed:</b> Concerns about complaints process, especially how a Complaint Team is made up, will be taken to the Engagement Working Group.	Engagement Working Group

Agenda Item 4	Focus group to obtain feedback on the Norfolk Autism Partnership documents with Tracey Walton	Action and Due Date
4.1	Chance for attendees to raise points for the attention of the Board and working groups.  <b>Noted:</b> The following themes were raised as part of discussion: <ul style="list-style-type: none"> <li>• Transitions, including child to adult, school to college/university, college/university to work.</li> </ul>	

	<ul style="list-style-type: none"> <li>• Support at University and college, especially for higher functioning autistic children and young people who may not have Education Health Care Plan (EHCPs).</li> <li>• Little or no support before an children's autism assessment .</li> <li>• Issues arising from autism not falling into Learning Disability or Mental Health funding streams.</li> </ul> <p>Positive stories about support for autistic students at UEA and City College, Norwich. How the use of reasonable adjustments and having the resources to deliver made a real impact.</p>	
4.2	<p><b>Noted:</b> Attendees reminded that if they wished to raise issues outside of the Forum, they be shared confidentially by contacting <a href="mailto:autism@norfolk.gov.uk">autism@norfolk.gov.uk</a>.</p>	

Agenda Item 5	Focus groups to obtain feedback on Autism Service Norfolk with Dr Cath Hai	Action and Due Date
5.1	<p>Dr Catherine Haig explained her role and the history of Autism Service Norfolk. She outlined the aims of the service and what it hopes to achieve in terms of assessment, pre- and post-diagnosis support, as well as current progress made. She answered questions from attendees about involvement of autistic people in Autism Service Norfolk recruitment process, diagnosis process and post-diagnosis tools available to help autistic people.</p>	
5.2	<p><b>Noted:</b> Attendees raised the following issues with the ASN leaflet:</p> <ul style="list-style-type: none"> <li>• Does not include information about pre-diagnosis support.</li> <li>• Does not include that funding is provided by CCG.</li> <li>• Formatting issues and colour choices make parts of the leaflet difficult to read, especially when using filters.</li> <li>• Important not to use “puzzle pieces” in any illustrations. Infinity loop used by NAPB to be considered.</li> <li>• Acknowledged the balance needed between looking attractive and providing detailed information.</li> <li>• Suggestion to add masking in public / meltdowns at home to characteristics list.</li> <li>• Suggestion to have more “positive quotes”.</li> </ul>	

	Issues raised regarding the lack of provision in both education and health services to be allocated appropriately to get resources to meet needs	
5.3	<b>Agreed:</b> Suggestions will be used to inform revisions.	Catherine Haig
5.4	<b>Agreed:</b> NAPB guidance on fonts, formatting, etc. will be sent to Catherine.	Administrator
5.5	<b>Agreed:</b> Consider adding additional options to consent and application forms to enable members to indicated if they are willing to be approached to be involved in interviews.	Engagement Working Group
5.6	<p>Catherine Haig explained purpose of Autism Service Norfolk questionnaire. The questionnaire is being redesigned following advice that it is too complex from the recent coproduction event held on the 22 Jan 2020. As part of focus group, Catherine compared the current version with one based on the NHS Family and Friends test.</p> <p><b>Noted:</b> The following feedback was generated:</p> <ul style="list-style-type: none"> <li>• One attendee preferred more options to express opinions, in line with original questionnaire.</li> <li>• Two attendees recommended making questionnaire as simple as possible if it is expected to be completed by autistic people without support.</li> <li>• Suggestion that a simple, less formal form is developed for autistic people and a more complex one for carers, but understood the challenges of this.</li> <li>• Suggestion for more prompt words and sentences to be added to comment boxes.</li> <li>• Suggestion for fewer blank spaces in revised version.</li> <li>• Consensus for use of colour and pictures.</li> </ul> <p>Overall preference for a combination of the original and revised questionnaire.</p>	
5.7	<b>Agreed:</b> Suggestions will be used to inform revisions.	Catherine Haig

<b>Agenda Item 6</b>	<b>Any Other Business</b>	<b>Action and Due Date</b>
6.1	Members asked that MPs are invited to ANF. They also suggested that attendees reach out to local politicians such as MPs Clive Lewis (Labour, Norwich South to increase publicity and influence local	Autism Administrator

	decisions on funding. General drive to get more outside involvement encouraged. <b>Noted:</b> Send invite to local MPs and councillors.	
6.2	Tracey Walton advised that there may be an opportunity to share experiences of specialist hospital provision in the coming months and asked if people would be interested. Attendees expressed interest in being part of this. Attendees raised no objections to being contacted as Autism Norfolk Forum members as part of an "autism involvement opportunity".	

<b>Agenda Item 7</b>	<b>Any Other Business</b>	<b>Action and Due Date</b>
7.1	<b>Noted:</b> Overall attendees expressed that the meeting felt very positive, useful, interesting and highly informative. Attendees commented that they appreciated a space where they felt listened to and understood. Catherine Haig was singled out for praise.  No issues raised regarding the NAPB Code of Conduct.	Autism Administrator

<b>Date, time and location of next meeting</b>
<ul style="list-style-type: none"> <li>• Tuesday 12 May 2020, 5-8pm. The Walks Stadium, Tennyson Rd, King's Lynn, PE30 5PB</li> <li>• Thursday 13 August 2020, 5-8pm. Ayton House, 11-17 Ayton Road, Wymondham, Norfolk, United Kingdom NR18 0QQ</li> <li>• Thursday 12 November 2020, 5-8pm. Great Yarmouth Town Hall, Hall Plain, Great Yarmouth, Norfolk NR30 2QF</li> <li>• Tuesday 9 February 2021. Time and venue to be arranged.</li> </ul>

## **Glossary**

ANF:	Autism Norfolk Forum
ASD:	Autism Spectrum Disorder
ASB:	Autism Service Norfolk
CCG:	Clinical Commissioning Groups
EHCP:	Education, Health and Care Plan
FOIA:	Freedom of Information Act
GDPR:	General Data Protection Regulations
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
WAW:	World Autism Week
WG:	Working Group
WG Lead:	Working Group Lead