



**Notes of the Autism Norfolk Forum (ANF) Meeting**  
**Held on: Thursday 31 October 2019, 10:30 – 13:30**

**Venue: County Hall, Norfolk County Council, Martineau Lane,  
Norwich, Norfolk, NR1 2DH**

**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)
Alan Hunter	NAPB member. Head of Community Children's Services, (Norfolk Community Health and Care)
Autism Administrator	Notes taker (NCC)
Bethany Slaughter	NAPB member (Norfolk Constabulary)
Trevor Key	NAPB member
Rosemary Boutet	NAPB member
Members of the public (5)	

<b>Agenda Item 1</b>	<b>Welcome and Introduction</b>
1.1	Welcome and Introductions made. Communication cards distributed, and their use explained. Directions to quiet rooms were given. Reasonable adjustments discussed.

<b>Agenda Item 2</b>	<b>Pre- and Post-Support for Children with Alan Hunter</b>
2.1	Alan Hunter gave a presentation on children's pre- and post-diagnosis support that is currently available and what is planned for the future. Alan Hunter explained the benefits of offering support and practical intervention before a diagnosis of autism is formally confirmed. Alan Hunter outlined some of the support is currently available:

	<ul style="list-style-type: none"> <li>• The <u>SEND Local Offer webpage</u> on Norfolk County Council's website gives many resources.</li> <li>• SLT, Health Visitors, Just One Norfolk, and ASD Helpings Hands can offer help.</li> <li>• Family Action Positive Behavioural Support (PBS) workshops are available.</li> <li>• Facebook groups can give more informal advice and support.</li> <li>• Private sector organisations can provide support for those willing and able to pay for it.</li> <li>• Schools are increasingly able to offer some help, support and advice.</li> </ul> <p>Alan Hunter explained that many of the same organisations also provide post-diagnosis support.</p> <ul style="list-style-type: none"> <li>• NCH&amp;C offers a post-diagnostic follow-up (PDFU) group to answer immediate questions, but only offers support up to the age of 18.</li> <li>• The Puffins Parent Programme is a parenting support programme for parents and carers of children/young people aged 5-19 years. This currently delivers 4 sessions until the end of December 2019 and will be delivered by a 3<sup>rd</sup> sector group from 1 January 2020. A catch-up service is to be offered. Puffins hopes to work with 180 families a year to meet the demand of newly diagnosed families. Puffins sessions will be themed.</li> <li>• The EarlyBird programme aimed at parents and carers of pre-school aged children will continue to operate.</li> <li>• NCH&amp;C hope to roll out an "Understanding my Diagnosis" programme soon.</li> </ul> <p>Alan Hunter indicated that the organisation ADHD Norfolk was being considered as a possible provider of autism training. Attendees expressed a strong dislike for this as the organisation is not ASD specific.</p>
2.2	<p>Discussion followed. Members of the public reported the following issues.</p> <ul style="list-style-type: none"> <li>• Schools may not understand signs of ASD, which has prevented children from being supported properly. Transitions to academies may have led to support being removed. Alan Hunter stated that post-diagnosis support is to be used in schools.</li> <li>• The NDS pathway is unclear.</li> <li>• While the Local Offer shows what is available, these resources are not used or are not used appropriately.</li> <li>• The ability for the ASD wellbeing service to provide ongoing support was discussed.</li> <li>• It was reported that getting support from Child and Adolescent Mental Health Services (CAMHS) for autism related conditions is extremely difficult, with prospective service users being sent "back and forth".</li> </ul>

	<ul style="list-style-type: none"> <li>Parents expressed the hope that services were more “joined up” in general.</li> </ul> <p>Questions were raised about the amount of money given for autism diagnosis. Alan Hunter responded that the money allotted for diagnosis is not for post-diagnostic support and as such his knowledge about it is limited. Efforts are being made to hire new staff to ensure nobody waits longer than 18 weeks for an assessment.</p>
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<b>Agenda Item 3</b>	<b>NAPB Update</b>
3.1	<p>Lee Gibbons (LG) provided an introduction to the Norfolk Autism Partnership Board, who is involved, how the partnership works, the governance of the Board and the process by which information is communicated from the ANF to the Board and working groups.</p> <p>Lee Gibbons read short reports from the NAPB working groups and took questions.</p>
	Concerns raised and acknowledged regarding sign-in sheet.
	Attendee expressed concern that commissioners from NCC and NHS were not present to give reports.
	<b>Action:</b> Invite commissioners to future ANF events.
3.2	<p><b>Workforce Development Working Group</b></p> <p>So far 1200+ NCC employees, the majority in Children and Adults Services, have undertaken basic training. The working group are exploring ways to bring this training to wider partners and other platforms, such as the NHS. Norfolk police have also taken an interest.</p> <p>Trevor Key, speaking as a member of the WG, responded to queries regarding quality of the training and service user involvement, speaking positively about the quality of training sessions he has sat in on.</p>
	<p><b>Action: Lee Gibbons will ask the WG Lead for answers to the following questions:</b></p> <ul style="list-style-type: none"> <li>What is the status of training accreditation?</li> <li>Does training meet the needs of people other than social workers.</li> <li>How much of the training is delivered by an autistic person and what is the nature of their contribution?</li> <li>Will eLearning and training be given to CCG employees?</li> <li>Can training be offered to people in the autistic community or organisations such as SENSational Families?</li> </ul> <p>Can training be offered to higher level staff at NSFT free of charge?</p>
	<b>Action:</b> On the recommendation of attendees, the NAPB will attempt to reach out to learning disability nurses at the Norfolk and Norwich hospital named Fiona and Gemma.

3.3	<p><b>Diagnosis Working Group</b></p> <p>An update regarding Adult Autism Diagnosis Service, with pre- and post-diagnosis support, was provided. A report on the service has also been submitted to Norfolk Health Overview and Scrutiny Committee (NHOSC) and recommendations will be worked on.</p> <p>An attendee raised criticism about various points in the NHOSC report, with emphasis on a lack of involvement by autistic people, concerns regarding accuracy of the report and a claim there was no pathway designed beyond March 2020.</p>
	<p><b>Action:</b> Criticism of the NHOSC report will be raised with the Autism Commissioner.</p>
3.4	<p><b>Data Working Group</b></p> <p>Following a presentation at the most recent Board Meeting, the Data Working Group will be looking to improve data collection.</p>
3.5	<p><b>Education Working Group</b></p> <p>Rosemary Boutet spoke about importance for autism training for staff in schools. Attendees shared their experiences of the challenges, especially at secondary schools.</p>
	<p><b>Action:</b> Concerns brought to Education and Workforce Development Working Groups.</p>
3.6	<p><b>Engagement Working Group</b></p> <p>A coproduction event with NAS has evaluated paperwork associated with the NAPB, including the Terms of Reference. Work arising from the event is still ongoing.</p> <p>Following the recommendations of the coproduction event, a new Code of Conduct for the Board, Working Groups and Forum has been created.</p> <p>The NAPB coproduced website has been made more user friendly for autistic members and other users. At the recent Board LG requested that WG leads regularly submit updates on the work of their group so that the website can be kept up-to-date. There was some criticism that the website is still not user-friendly enough.</p> <p>The WG is producing a newsletter.</p>
	<p><b>Action:</b> Engagement WG will look again at NAPB webpage.</p>

<b>Agenda Item 4</b>	<b>Open Forum for Discussion</b>
4.1	<p>LG led open discussion on topics which had not already been talked about at the meeting and which participants would like the Autism Partnership Board to investigate further.</p>

	<p>Concerns raised regarding CAMHS and support for autism-related conditions. It was requested that the following concerns were investigated:</p> <ul style="list-style-type: none"> <li>• CAMHS is not commissioning for autism services, particularly in children. They have repeatedly ignored referrals from paediatricians regarding eating disorders and eating/anxiety conditions which are a consequence of their autism. Report this is a consequence of eligibility criteria – support can be given for stress and anxiety if it is unrelated to autism, but not if the conditions are linked.</li> <li>• CAMHS signposting is inadequate. Voluntary organisations which are signposted to may not have necessary expertise. Vital information is not shared with parents; specific example given about existence of Individual Payments.</li> <li>• There does not appear to be a single list of private professionals who can diagnose autism and autism related conditions. This would be a helpful resource.</li> </ul> <p>Suggestion made that a CAMHS professional should be recruited to join the NAPB to help address these concerns.</p>
	Participants generally agreed that having a team focussing on ASD would be helpful in addressing concerns and ensuring high quality communication, as autism does not fit well in the current models for Learning Disabilities or Mental Health.
	General agreement that problems occur and become worse thanks to a lack of early intervention and successful transitions process.
	Several participants expressed strong concerns about current autism service provision, a lack of reasonable adjustments and enablement services.
	<b>Action:</b> Specific content of complaints will be raised with appropriate Commissioners.
	Concerns raised about new Terms of Reference's lack of clarity surrounding what being a "full member" means.
	<b>Action:</b> Engagement WG will look again at the Terms of Reference and ways to communicate changes.

Agenda Item 5	Wellbeing Check
5.1	Attendees reported that the meeting was useful, productive and well-structured. One attendee noted that this meeting was managed better than the last one they attended. Several attendees suggested holding future meetings at a more autism-friendly and "relaxed" venue than county hall. Attendees suggested advertising the meetings more widely.

	<b>Actions from the Meeting</b>	<b>Action and Due Date</b>
<b>Action 1</b>	Invitations to future ANF events to be extended to NCC and NHS commissioners.	NAPB Engagement Working Group
<b>Action 2</b>	Questions will be submitted to Workforce Development WG for answers.	Workforce Development Lead
<b>Action 3</b>	Attempts will be made to reach out to N&N nurses "Fiona" and "Gemma".	NAPB Engagement Working Group
<b>Action 4</b>	Criticism of the HOSC report will be submitted to the Autism Commissioner.	Autism Commissioner
<b>Action 5</b>	Leads for the Education and Workforce Development WGs will meet to discuss future partnership.	Working Group Leads
<b>Action 6</b>	Engagement WG will re-examine NAPB webpage, Terms of Reference and other communications.	Engagement WG Lead

<b>Date, time and location of next meeting</b>
<ul style="list-style-type: none"> <li>• Wednesday 12 February 2020, 5-8pm. Aylsham Town Hall, Town Hall, Market Place, Aylsham, NR11 6EL</li> <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> </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