



**Notes of the Autism Norfolk Forum (ANF) Meeting
Held on: 21 September 2021**

**Venue: The Vernon Castle Room, Norwich Millennium Library,
Millennium Plain, Norwich NR2 1AW and online via Zoom**

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	NAPB member and Engagement Working Group Lead (ASD Helping Hands)
Tom Bassett	Partnership Board Transformation manager
Kirsten Haywood	Note taker (NCC)
Members of the public	23 (in person and on Zoom)

Agenda Item 1	Welcome and Introduction
1.1	Welcome and introductions made: <ul style="list-style-type: none">• Communication cards distributed, and their use explained.• Fire exits and alarm procedures outlined.• Acknowledged a note taker is provided.• NAPB Code of Conduct introduced and explained.• Co-Production Principles outlined.

Agenda Item 2	Update from the Board
2.1	<p>Lee Gibbons gave an overview of the purpose and structure of the Board:</p> <p>The Norfolk Autism Partnership (NAPB) was set up 2016 in response to the National Autism Strategy. It aims to make Norfolk a more friendly and accepting place for people with autism. There are currently 5 different working groups that feed into the board: Engagement, Diagnostics, Workforce Development, Document Update, and Employment. These working groups report directly to the NAPB. The NAPB reports to the Health and Wellbeing Board.</p> <p>The Partnership Board is Independent of Norfolk County Council (NCC) and any other statutory bodies. It has an independent website, which is</p>

	managed through the Engagement Working Group. Lee gave information on how to sign up to the Partnership.
2.2	<p>Recent activities of the NAPB Board include:</p> <ul style="list-style-type: none"> • Collating the results of a Survey on how people with autism had coped during the pandemic, which the Clinical Commissioning Groups (CCG) have used to support their work. • The Board had planned to hold an exhibition in King's Lynn for World Autism Week. However, this had to be rearranged because of the pandemic. It was replaced by a weeklong virtual event. Over the course of the week, webpages on the Partnership site to do with the event were visited around 900 times and videos viewed 400 times, • The Board is currently looking at different ways of engaging with the people with autism in the community. The plan is to look at more informal engagement events, as people prefer this to the formality of a Forum. • There are plans to ensure an 'Autism Champion' in every Norfolk library. These champions will be properly trained, can be consulted on best practice, and will be able to provide support for networking. • The Board now offers two different types of training: e-learning and a one-day, in-person course on 'Understanding Autism'. Training is reviewed every 6 months. The e-learning is available on the NCC internal training platform, where it has been completed by 4305 members of NCC staff, as well as the Partnership website. • One of the key focuses for the Board is autism diagnosis. The Board understands there has been a 140% increased investment in the service. No child must wait more than 52 weeks for their initial assessment. • The Board has also worked with the Adults Safeguarding Board on mutually beneficial topics, such as the launch of the Tricky Friends initiative.

Agenda Item 3	Q&A/Feedback from the Public
3.1	<p>Lee and Tom opened the discussion to the public in the meeting room and on Zoom. The questions and responses were as follows:</p> <p>Q. Is the 52 weeks diagnosis time an interim target which you are aiming to bring down?</p> <p>A. The aim is always to get it lower. People are now being diagnosed quicker, but there are also more people entering the service.</p>

	<p>Q. Once diagnosed, people need help to cope with their extreme anxiety (adults). Where can they get help for this?</p> <p>A. After the break there will be information about this. Norfolk do have a post-diagnostic support package.</p> <p>Q. What about if you are diagnosed privately – are you entitled to any post-diagnostic support? People are made to jump through further hoops if they have not been diagnosed by the NHS, as their Autism identification is not accepted (specific example given of EHCP).</p> <p>A. EHCP should be needs based, not diagnosis based. Inform them of this and point to the documentation if anyone is withholding support.</p>
3.2	<p>Attendees also commented that:</p> <ul style="list-style-type: none"> • Mental health teams do not always understand Autism Spectrum Disorder. Attendee referred specifically to their experience with Norfolk and Suffolk NHS Foundation Trust (NSFT). • Although there was a long and lonely waiting time for a diagnosis, the post-diagnostic support package was excellent. • Traditional CBT is not helpful for those with Autism. NSFT's Recovery College still does not have sessions and should be pushed to achieve this. • Norfolk integrated housing and community support service (NIHCS) was helpful. • It is important to get waiting times down for children, especially for girls as they often go unseen and blend into a classroom environment.

Agenda Item 4	Presentations from Partner Organisations
4.1	<p>Kate Draycott, Family Voice:</p> <ul style="list-style-type: none"> • Kate works for Family Voice. She is a mother of two children with special needs. • Family Voice provide support to people aged 0-25. • Recent activities include: 'Let's talk' sessions on zoom; creating and sharing surveys; coffee mornings, which the NAPB are hoping to get involved with.
4.2	<p>Kerry, Carers Matters:</p> <ul style="list-style-type: none"> • Carers Matter are commissioned by NCC to do carers assessments. They also provide an advice line and community

	<p>support team, who give information and advice, and signposting to other services.</p> <ul style="list-style-type: none"> • A carers assessment will discuss the carer's well-being and ask: "Do they have anything additional that they need support for?" and "Would they like to access a grant?" • Anyone can refer a carer via the advice line or the website. A carer can come directly to Carers Matter for an assessment, they don't have to go through NCC.
	<p>Q. <i>What support is there for those whose child no longer lives with them, but would still need some sort of support? These parents experience Guilt, tiredness, etc.</i></p> <p>A. They could benefit from a Carers Voice membership, and locality-based carer support groups.</p> <p>Q. Kate Draycott (Family Voice representative) commented that there is no support for someone with a single disabled child. If the individual has a sibling, they would receive support as a 'young carer'. This would mean the disabled child would receive support at 18, but before this point there will be no support.</p> <p>A. Kerry agrees that this is a problem</p>
4.3	<p>Lee Gibbons, Helping Hands:</p> <ul style="list-style-type: none"> • ASD Helping Hands was set up by Lee's mother to help support her two autistic sons. • The group is funded by donations and grants - ASD Helping Hands do not engage in contracts with statutory bodies. • There are no age limits or geographical restrictions on who can go to them for help. • Everyone who works for the organisation is either is on the autistic spectrum or has a family member or partner who is. • They run support groups across Norfolk: Aylsham, Norwich, Thetford, Dereham. • They appeal benefits, provide support with housing needs, put people in contact with other organisations, provide ADD and PDA support, and information about challenging behaviour and challenging situations. • Commonly reported concerns by parents are: Communication, sensory issues, behaviour, and a lack of understanding around what autism is. • There is a simple referral form on the Helping Hands website

Agenda Item 5	Final Comments and Questions
5.1	<p>Final opportunity for discussion raised the following questions and comments from members of the public:</p> <p>Q. <i>It would help to have the opportunity to speak with other autistic adults, as it can be a very lonely time when you are diagnosed. Are there opportunities for this?</i></p> <p>A. Asperger's East Anglia run groups specifically for people with Autism. NCC's new library Autism Champions are also intended to help with this.</p> <p>Q. <i>High functioning autistic individuals are finding it hard to access long term meaningful employment. How many organisations employ autistic individuals?</i></p> <p>A. Helping hands: We have lots of volunteers who are on the spectrum, diagnosed or undiagnosed.</p> <p>A. Carers Matter: many of our members are carers or have been carers. But it is not an Autism specific service</p> <p>A. Family voice: We are all parents of special needs children. But it is not Autism specific.</p> <p>A. APF: We would not have any event or board that did not have representation from those with Autism. The employment working group has just started, and they want to understand what the challenges are there.</p>
5.2	<ul style="list-style-type: none"> • People with Autism need more help to cope with anxiety and depression, and so need improved Mental health services. Suicide rates are higher than in the general population. Tom agreed to take this issue to upcoming board meetings. • Members of the public agreed that the hybrid meeting was successful.
5.3	<p>Partnership Co-chair Trevor Key confirmed that the next Partnership Board meeting will take place on October 13 2021. As part of the agenda it will cover the National Strategy for Children and People with Autism and hear from the Safeguarding Board chair on recent events at Cawston Park Hospital.</p>

	Actions from the Meeting	Action Holder and Due Date
Action 1	Mental health issues will be prioritised on future Board and Forum agenda.	Tom Bassett

Date, time and location of next meeting
Future Autism Forums are still being arranged. It is hoped the next meeting will be in January 2022. More details will be released in time.

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