



Notes of the Autism Norfolk Forum (ANF) Meeting
Held on: Wednesday 27 November 2019, 11:00 – 13:30

**Venue: 7th King's Lynn Scout Group, Portland Place, King's Lynn,
PE30 5LZ**

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

Name of Attendee	Organisation and/or Role
Tracey Walton (TW)	Autism Commissioning Manager, Adult Social Services - Norfolk County Council (NCC)
Lee Gibbons (LG)	NAPB member and Engagement Working Group Lead (ASD Helping Hands)
Dearbhla Quinn (DQ)	Specialist Speech and Language Therapist, Children's, Young People and Adult Specialist Services.
Autism Administrator	Notes Taker (NCC)
National Autistic Society (NAS) West Norfolk Members	12

Agenda Item 1	Welcome and Introduction
1.1	Karan Mckerrow and the NAS West committee welcomed attendees. Attendees introduced themselves and their interest in autism. Communication cards were distributed, and their use explained. Directions to quiet rooms were given. No reasonable adjustments were requested.

Agenda Item 2	Explanation of NAPB Governance
2.1	Karan Mckerrow provided a brief history of NAS West and its involvement in the precursors to the NAPB was given.
2.2	Tracey Walton explained the structure of the Board, its working groups, and their relationship to the Autism Norfolk Forum (ANF, formerly NAPG). She explained the process by which themes can be fed from Forums to the Board and the working groups to address.

2.3	Tracey Walton explained that ANF meetings are arranged on a quarterly basis following Board meetings and held in different Norfolk localities each time. She apologised for the delays in scheduling an ANF meeting in the Western locality and explained that this meeting would not affect the scheduled West Norfolk ANF meeting on 12 May 2020.
2.4	<p>Tracey Walton explained that there are many ways to engage with the partnership from regular email communications to Board membership.</p> <p>In response to questions, Tracey Walton noted that based on feedback from attendees and the nature of forums it is difficult to set up teleconferencing facilities at forums. It is also difficult to arrange full forums more regularly in the West ensuring the right expertise are available to respond to the range of views. As a compromise, it was agreed that the agendas for upcoming Forum meetings will be sent to NAS West via Karan Mckerrow. This will allow a local discussion to be set up and a nominated individual will take concerns and questions to the Forum itself.</p>

Agenda Item 3	Welcome and Introduction
3.0	Tracey Walton and Lee Gibbons explained the purpose of the five currently running working groups and their progress to date.
3.1	Data Working Group is developing a partnership autism dashboard to collate a wide range of autism-related data from across the partnership into one, easily accessible point. Once completed it will allow appropriate services to be commissioned priorities targeted appropriately.
	<p>Tracey Walton answered questions from the audience.</p> <ul style="list-style-type: none"> • She gave assurances that with the approval of the autism strategy progress is now being made and that resources from the partnership have been allocated to complete this work. • Aligned to the strategy we need to understand what we are want to achieve and then what we need to measure to evidence success. It is suggested we gather easily accessible sources first, such as social service case management systems. Decisions will then be made about what other data is required and how best to gather it and what resources will be needed to do this. • Some of the challenges are, what we may want to measure may not be recorded in a way we are able to obtain it. For example, schools report to the DfE on school attendance and exclusions, but don't record health status of autism, as it is not part of the information, they are obligated to record for the DfE. • NAS West raised concerns of autistic people being excluded from day services and asked that this is measured. • NAS West raised concerns of the lack of support for autistic people in the west with many facilities closed.

	Concerns raised of lack of resources for autistic people with anxiety.
	Tracey Walton encouraged all to complete and spread the forthcoming whole adult life questionnaire as the results will be an important source of data.
3.2	<p>Workforce Development Group has coproduced eLearning-based autism training and specialist face to face training. The workforce development working group is now aligning the training to the skills for care. The training is being rolled out to social care staff and offered to wider partners. E-learning basic awareness training will be offered free of charge to partner organisations. Specialist face to face training material will be offered free of charged with confirmation of co-delivery with autistic person and specialist trainer.</p> <p>Training will be accredited by UEA, who will also be rolling it out to students and staff.</p>
	Action: Tracey Walton will put Tom Bassett in touch with Karan Mckerrow to organise a training session for NAS West Norfolk. This will be achieved when Tom Bassett is back from leave early February.
3.3	<p>Engagement working group is working on a number of projects to increase engagement with the Board across the county.</p> <ul style="list-style-type: none"> • Developed Adult Autism questionnaire, hopes to be released soon as part of official launch of the Autism Strategy. • NAPB and ANF webpages on NCC website have been streamlined and made more user-friendly, with minutes added to them as they are approved. • Working to discover and connect with smaller groups providing support across the county. • A buddy scheme for NAPB members is being implemented. • Terms of reference have been reviewed. • Volunteer agreements are being developed to make clear roles of volunteers, out of pocket expenses and what is required to support them. • An NAPB newsletter is being developed. • A successful awareness raising event at the Forum in Norwich for World Autism Week was held this year. A similar event in 2020 is planned to be held in West Norfolk. <p>Membership forms to gain more information about the work of the Board as well as to join</p>
	<p>Lee Gibbons and Tracey Walton answered questions from the audience</p> <ul style="list-style-type: none"> • Adult autism questionnaire can be answered by the parents or carers of autistic people aged 18+ • Although running a second questionnaire aimed at children with autism is a possibility, the current plan is to work together with EHCP staff to gather the relevant data. This will prevent duplication of effort.

	<ul style="list-style-type: none"> • The NAPB is not currently on social media as it was found to be too resource intensive to maintain. The NAPB asks recipients of their communications to spread widely. • NAS West members expressed strong criticism of the current code of conduct and suggested it be reduced to one page. Tracey Walton welcomed the feedback and will work with the Engagement Working Group to make improvements. <p>NAS West members requested that the need to sign up to the code of conduct is removed from both the application and consent form, as they felt it represents a barrier for autistic people to get involved.</p>
3.4	The Education group was found to be ineffective and simply duplicating work done elsewhere. Once the implementation plan for the SEND Strategy is agreed the NAPB will identify opportunities for engagement.
	Discussion was had about different autism specific / complex needs schools and the specific issues facing West Norfolk. Importance of education, identification and early intervention emphasised.
3.5	The Diagnosis group is providing scrutiny on the ASN improvement plan to reduce the waiting list and shape pre and post diagnosis support. The service is currently recruiting staff and shaping pre and post-diagnosis support. NAS West members indicated that it is unclear where individuals or their supporters should go for an autism diagnosis. Tracey Walton advised that people can self-refer to ASN and advised both the information for the children's and adults services is on the Heron Website and NAPB webpage. Tracey Walton asked NAS West to spread the word.
	<p>Dearbhla Quinn gave a progress update on child diagnosis, summarised the diagnosis process and outlined current provision for pre- and post-diagnostic support.</p> <ul style="list-style-type: none"> • Workshops for under-sixes focusing on communication needs and toileting. • Shorter two-hour workshops post-diagnosis focussing on theories and strategies. • Puffins five-week course for parents, replacing Early Birds. • Recruitment and retention of staff has been a major concern, but nine additional new staff including OTs, SALT, and psychologists have been found. • The service is currently focussed predominantly on providing diagnoses rather than support, but work is being done to change this. <p>DQ noted that while assessments for children are usually undertaken at school to allow observation in a variety of settings, the service is aware of masking behaviour and that home visits can be arranged.</p>

Agenda Item 4	Norfolk Autism Strategy “My Autism, Our Lives, Our Norfolk”
4.1	<p>Discussion around autism strategy. Although reception was generally very positive, three main points arose:</p> <ul style="list-style-type: none"> • NAS West members strongly disliked the phrasing used on p. 11 of the Easy Read Strategy. They strongly suggested finding alternative language for “difficult behaviour”. • The easy read version of the strategy does not have a section on sensory needs as in the full version. • P. 28 of the full version of the strategy lists states the NAPB will “Ensure the appropriate identification and management of demand avoidance to prevent an escalation to pathological demand avoidance”, but attendees noted that this is not currently happening. Tracey Walton clarified that this is one of the aims of the strategy rather than something achieved so far.

Agenda Item 4	Norfolk Autism Strategy “My Autism, Our Lives, Our Norfolk”
5.1	NAS West brought up issues surrounding accessing CAMHS resources in West Norfolk. Tracey Walton will raise this within the diagnosis working group.

	Actions from the Meeting	Action and Due Date
Action 1	Process consent forms from meeting	Administrator
Action 2	Tracey Walton will take themes from meeting to relevant Working Groups and next Board meeting.	Tracey Walton
Action 3	Tracey Walton will put Karan Mckerrow in touch with Tom Bassett to discuss NAS West training	Tracey Walton
Action 4	Ensure Claire at Family Action is added to relevant contact lists.	Administrator
Action 5	Agendas for Forums meetings will be sent to NAS West via Karan Mckerrow ahead of time to allow local discussion.	Administrator
Action 6	Tracey Walton will make enquiries about CAMHS in West Norfolk.	Tracey Walton

Date, time and location of next meeting
<ul style="list-style-type: none">• Wednesday 12 February 2020, 5-8pm. Aylsham Town Hall, Town Hall, Market Place, Aylsham, NR11 6EL• Tuesday 12 May 2020, 5-8pm. The Walks Stadium, Tennyson Rd, King's Lynn, PE30 5PB• Thursday 13 August 2020, 5-8pm. Ayton House, 11-17 Ayton Road, Wymondham, Norfolk, United Kingdom NR18 0QQ• Thursday 12 November 2020, 5-8pm. Great Yarmouth Town Hall, Hall Plain, Great Yarmouth, Norfolk NR30 2QF• Tuesday 9 February 2021. Time and venue to be arranged.

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