



**Notes of the Norfolk All Age Autism Partnership Group (NAPG)
meeting**

Held on: Thursday 1 August 2019, 17:00 – 20:00

Venue: The Priory Centre, Priory Plain, Great Yarmouth, NR30 1NW

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 Engagement Working Group Lead & ASD Helping Hands
Tracey Walton	NAPB Autism Lead & Autism Commissioning Manager (NCC)
Chloe Cullen	Youth Council Representative (NSFT)
Catherine Haig	Autism Service Norfolk
Lisa Lonergan	Family Voice
Clare Smith	Norfolk Autism and Asperger's Network, NSFT Green Light Champion NSFT Governor
Stephen Durrance	NAPB member
Bruce Hubbard	NAPB member
Members of the public (3)	

Agenda Item 1	Welcome and Introduction
1.1	Lee Gibbons welcomed everyone to the meeting and made introductions. Lee Gibbons advised attendees of the location of the quiet room and other facilities within the building. Tea, coffee and biscuits were made available. The room temperature was checked, and a fan obtained from reception.
	Communication cards were made available and their use explained. Lee Gibbons checked if any other reasonable adjustments were required; none raised.

Agenda Item 2	NAPG Questions and Answers
2.1	<p>The NAPG Questions and Answers were provided to those in attendance.</p> <p>Action: Autism Administrator will distribute all new NAPG questions and answers 10 days in advance of the NAPG meeting to all NAPG members.</p>
2.2	<p>Question 8: Clare Smith advised that Question 8 had not been answered. Tracey Walton advised that the Co-Chairs are named and while we can name statutory members we may need to seek the permission of autism representative to publish their names.</p> <p>Action: The NAPB will seek permission of autistic members and where permission is granted names will be added to the NAPB website.</p>
2.3	<p>Question 7: Clare Smith advised that a report from the NAPB to the NAPG had not historically happened. She asked if, as stated in the terms of reference, a report from the NAPG will be going to the NAPB? Tracey Walton reminded Clare Smith of the NAPB report provided at the 14th May NAPG and confirmed that historically NAPB reports had been provided at all NAPG meetings. She further advised that an update from the NAPG is provided at each NAPB meeting. Clare Smith stated that she did not recall this, or it was not communicated in a way she acknowledged it. Lisa Lonergan advised that the briefing had been provided for those meetings she attended.</p> <p>Action: Brief notes and actions from the NAPG will be provided from this point onward.</p>
2.4	<p>Question 6: Clare Smith asked if Cllr Bill Borrett had apologised to NAS West Branch? Tracey Walton advised that the local autism strategy was sent to NAS West Branch on two separate occasions. She had also discussed the strategy in face to face meetings and in email exchanges with NAS West Branch representatives, allowing comments and changes to be made to the strategy on day services, education and blue badges.</p> <p>Action: Organisations to distribute to their members in ways and times that suit them NAPB communications.</p>
2.5	<p>Question 1: Clare Smith asked why it has taken over 6 weeks to obtain an answer to this question. Lee Gibbons advised that the question had been circulated to obtain an answer. Once it has had been received, it will be sense checked by the Education Working Group and added to the questions and answers document.</p> <p>Action: Autism Administrator to chase an answer and add to the NAPB FAQ.</p>

Agenda Item 3	NAPB Update
3.1	<p>Lee Gibbons read out the NAPB update and advised all information is available on the NAPB website.</p> <p>Clare Smith queried why the Autism Strategy is going to Cabinet but not health. Tracey Walton advised that the local autism strategy is going to Joint Strategic Commissioning Committee (JSCC) in August.</p> <p>Links to the agenda, minutes and reports for the Health and Wellbeing Board can be found at: https://www.norfolk.gov.uk/what-we-do-and-how-we-work/policy-performance-and-partnerships/partnerships/health-partnerships/health-and-wellbeing-board/search-reports</p> <p>Links to the agenda, minutes and reports for Cabinet can be found at: https://www.norfolk.gov.uk/what-we-do-and-how-we-work/councillors-meetings-decisions-and-elections/committees-agendas-and-recent-decisions/cabinet</p>
3.2	<p>Engagement Working Group</p> <p>Lee Gibbons advised that attempts to convert the adult questionnaire into easy read had not been successful, making it too long and impossible for anyone to complete. For this reason, an easy read introduction will be produced that will include details about the questionnaire, what it aims to achieve and where people can go to get support.</p> <p>The Working Group is currently updating the NAPB website to ensure it is autism friendly. It is also working on the next NAPB newsletter.</p>
3.3	<p>Workforce Development</p> <p>Clare Smith queried whether the CCG are funding the autism training.</p> <p>Action: Raise at Workforce Development Working Group and add to the NAPG questions and answers.</p>
3.4	<p>Diagnosis Working Group</p> <p>Lee Gibbons provided an update on the Diagnosis Working Group. Catherine Haig added to this, advising that Asperger's East Anglia had decided not to continue with their contract. Advising that pre- and post-support was a bigger demand on resources than expected, the waiting list going up and funding not matching demand.</p>
	<p>Clare Smith advised the NAPG that Norman Lamb MP had hosted a meeting with NAAN, NCH&C and NCC, where it was advised that funding is being moved to NCH&C. There will be no additional increase in funding. NCH&C are appointing an additional clinical psychologist, speech and language therapist and 1.2 support workers.</p>
	<p>Chloe Cullen advised the NAPG that everyone she knows had to go private and pay for an autism assessment as a result of not getting through the screening tool. This is particularly a problem for females,</p>

	<p>who do not meet the assessment criteria, due to masking that leads to females getting misdiagnosed. A member of the public advised, with full acknowledgement from all NAPG members, that recently diagnosed autistic people need to better understand their condition (for example levels 1 through 3), what their needs are and what type of support could help them.</p> <p>Action: Catherine Haig welcomed the feedback and will consider this in the future when writing diagnosis letters.</p>
	<p>Discussion regarding GPs being a gate keeper but having a lack of awareness or knowledge of autism (despite some believing they are the experts), creates a barrier to diagnosis. Tracey Walton advised people can self-refer to the Autism Service Norfolk for adult diagnosis.</p> <p>Action: Members to share the link to self-refer to Autism Service Norfolk http://www.norfolkcommunityhealthandcare.nhs.uk/The-care-we-offer/Service-search/autism-service-norfolk.htm.</p>
	<p>Chloe Cullen advised that the diagnosis service needs to check how people are getting on while they are on the waiting list for an autism diagnosis assessment. This is because an individual's needs can change over time and as a result may now need a priority assessment.</p> <p>Action: Catherine Haig to consider as part of continued service improvement.</p>
	<p>The NAPG members discussed people needing tailored individual and group pre- and post-diagnosis support in age ranges from young adults (18 – 24), adults (25 – 40), older adults (41 – 64), older people (65 plus). Named peer support workers are required who have autism knowledge, a wide range of general knowledge and know who to contact for housing, social care and health – an “all-round go getter”.</p> <p>Action: Tracey Walton to feed into Diagnosis working group and ASN Contract Monitoring discussions.</p>
3.5	<p>Data Working Group</p> <p>Lee Gibbons updated on progress of the Data Working Group advising that an autism dashboard is being created. Tracey Walton confirmed data will include information from wider partners and not just NCC.</p>
3.6	<p>Education Working Group</p> <p>Bruce Hubbard provided an update on the Education Working Group. He advised that while progress has been slow a detailed plan is now in place. Clare Smith requested the details of the plan, to which Bruce Hubbard advised there is too much information to go into the detail in this group. He assured the NAPG that work is progressing with many different coproduction opportunities ahead.</p>

Agenda Item 4	NAPB Group Themes
4.1	This part of the meeting was to give an opportunity for autistic people to raise concerns that they had and potential barriers to services, with the aim of taking them back to the NAPB for further discussion. It was also an opportunity to outline things which were going well, so that they are taken into consideration in future plans.
4.2	<p>Gaps in Service</p> <p>It was reported that there is currently no support for autistic people in need of work-based skills training, housing knowledge, tax information and benefit advice.</p> <p>Chloe Cullen recommended the Living Well with Autism course and directed NAPG members to an article on her twitter feed “sillybillychloe”, https://twitter.com/sillybillychloe/status/1155188657227276290/photo/1</p>
4.3	<p>DWP Assessment</p> <p>Issues regarding dealing with the DWP and assessments were raised, particularly a lack of quiet rooms, problems with strip lighting and a general lack of awareness of the needs of autistic people. It is reported that no reasonable adjustments are being put in place. Autistic people are being told they are not being assessed and that the person interviewing them is “just asking some questions”, but when the paperwork comes through it says, “in your assessment”.</p>
4.4	<p>Prison</p> <p>Discussion regarding the lack of autism diagnosis and support for people with autism and or autistic traits within prisons. Discussion regarding the case of an autistic person discharged from a Norwich Prison being handled incorrectly, where the autistic person was delivered outside of the prison with no preparation or support put in place. By the time they got home to Suffolk they were anxious with everything re-surfacing. On presentation to Suffolk council for housing they were directed to a roundabout where other homeless people were living rough.</p>
4.5	<p>Social Care Team</p> <p>It was reported that autistic people are getting bounced between mental health and learning difficulties teams, frequently either classed as not meeting criteria or classed as too high functioning and therefore ineligible to access services. Tracey Walton advised that if a service user has autism and mental health issues, the Mental Health team will support them; if they have autism with a learning difficulty the Learning Disabilities team will support them. Chloe Cullen talked about psychologists who are finding it difficult to identify the correct team for their service user.</p> <p>Action: Chloe Cullen to seek permission of the affected individual and forward their details to Tracey Walton at autism@norfolk.gov.uk.</p>

4.6	<p>Living Skills</p> <p>It was reported that autistic people need support to learn living skills such as cooking, cleaning, management of finances/bills, and identifying ways to protect themselves from being taken advantage of.</p>
4.7	<p>Autism safeguarding</p> <p>There was discussion around autistic females being sexually and/or financially abused. It was reported that it is “a dangerous world for them”.</p>
4.8	<p>Pre- and Post-Support</p> <p>Action: Recorded separately and will be reported into the Diagnosis Working Group.</p>
4.9	<p>Training</p> <p>It was reported that more people/professionals need more training in autism, especially around females who are able to mask. Consideration should be given to employing people to deliver services who have autism and lived experience. Autistic people tend to trust and have a sense of relief when being supported by a person with autism or lived experience.</p>
4.10	<p>Carers Respite/Support</p> <p>It was reported that families are struggling to support their children, with young autistic adults particularly feeling like a burden to their parents and families. Support is needed for the families of autistic people. Support is needed for those who choose to live away from home as well as for those who stay, due to the high level of support needed to live independently.</p>
4.11	<p>Accessibility</p> <p>It was reported that support to access services is needed for autistic people and should not be determined by a period of time provided.</p>
4.12	<p>Bereavement Services</p> <p>Discussion regarding a lack of bereavement services and reasonable adjustments to enable autistic people to properly engage. Limited 6 sessions of counselling is not enough for autistic people who find it difficult to express their emotions. An autistic NAPG member advised that they were discharged as they were told their needs could not be met as they were unable to delve deep enough into their emotion and that they were banned from saying the word autism.</p>
4.13	<p>NSFT Wellbeing Service</p> <p>NAPG member advised that the NSFT are trying to resolve issues regarding autism but are also limited to 6 sessions with a councillor.</p>

Agenda Item 5	Wellbeing Check
5.1	Generally reported that the first half of the meeting, involving the Questions and Answers and the NAPB update, created a tense uncomfortable atmosphere. The second half, the pre- and post-support workshop, was very productive and informative with a friendlier environment. Clare Smith advised that Lee Gibbons style less formal that supported a friendly and welcoming environment.

	Actions from the Meeting	Action and Due Date
Action 1 01/08/19	Autism Administrator will distribute all new NAPG questions and answers 10 days in advance of the NAPG meeting to all NAPG members.	Autism Administrator
Action 2 01/08/19	The NAPB will seek permission of autistic members and, where permission is granted, names will be added to the NAPB website.	NAPB Board
Action 3 01/08/19	Approach autistic voluntary and informal groups to ask them to reach out to their audience in ways that work for them to communicate the NAPG meetings.	Engagement Working Group
Action 4 01/08/19	The question ““Will the CCG funding the autism training?” will be asked at the Workforce Development Working Group. An answer will be provided through the NAPG questions and answers.	Workforce Development Working Group
Action 5 01/08/19	NAPG Questions and Answers, 1 to be obtained and sense checked by the Education Working Group and added to the questions and answers document.	Education Working Group

Date, time and location of next meeting
<ul style="list-style-type: none"> Thursday 31 October 2019, 10:30am–1:30pm. County Hall, Norfolk County Council, Martineau Lane, Norwich, Norfolk, NR1 2DH 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

Appendix: NAPG Questions and Answers

Topic	NAPG Meetings
<p>Question 10</p>	<p>A mere two weeks before the next meeting, you circulate this email, changing the location and, more critically, the time from the morning to an evening meeting. And you do so without even acknowledging the change or apologising for it. I suppose you expect anyone's who's made arrangements to simply unmake them, bear any additional cost and/or simply not attend. NAPG Member 29th July 2019</p>
<p>Answer 10</p>	<p>The Norfolk Autism Partnership Group (NAPG) webpage of the Norfolk County Council website records the dates, times and locations of upcoming meetings -</p> <p>https://www.norfolk.gov.uk/what-we-do-and-how-we-work/policy-performance-and-partnerships/partnerships/all-age-norfolk-autism-partnership-board</p> <p>Under the dates listed the following warning is given:</p> <p><i>Please note that while we do our best to maintain the dates and times listed above, due to changing circumstances they may be subject to change. Please check this page regularly for any updates.</i></p> <p>Unfortunately, the venue the Norfolk Autism Partnership Board (NAPB) originally booked for the 1st August NAPG meeting cancelled. The reason the venue cancelled the booking was due to a problem with the lift and building maintenance that could cause issues for people visiting and using the venue. We have worked hard to ensure we retained the date but needed to change the time and venue to accommodate the meeting at the new venue.</p> <p>To prevent confusion we issued the date, time and venue as we usually would through the NAPG mailing list, giving 10 days' notice alongside updates to the website. Historically when Autism@norfolk.gov.uk has highlighted or apologized for any changes, people have reported being very confused and it has caused more problems than it solved, with people turning up at the wrong time or venue.</p> <p>The NAPB has confirmed it does not pay expenses for NAPG meetings as they are public forums that people can choose to attend and have their voice heard.</p>

Topic	NAPG Meetings
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Question 9	Yet again we would not be able to attend this meeting because on this occasion it is located 66 miles from us so a 132 mile round trip. This is unacceptable and yet again we are having to ask why meetings are not held in the centre of the county? We feel that we are being deliberately isolated in this regard because we have been asking for the same thing since Derek Holdsworth was Chair. NAS West Norfolk 29 th July 2019
Answer 9	The NAPB sincerely apologises and promises that this has not been done deliberately. The NAPB is working with the NAS West Branch to identify an autism friendly venue, date and time and proposes to put an event on in the Western Locality as soon as possible.

Topic	NAPB Membership
Question 8	Who is now on this committee, who is Chair etc please? NAS West Norfolk 29 th July 2019
Answer 8	<p>The NAPB has been running for just over a year. The Partnership is coordinated by a Partnership Board, which meets quarterly and whose membership comprises autistic people, family carers and representatives from public sector and third sector organisations. There are 25 members, of whom 9 are autistic people or family members/carers of autistic people. With an expression of interest to join the Board, members of the public are welcome to observe board meetings. This can be arranged by contacting Tracey Walton.</p> <p>James Bullion is the Local Authority Co-Chair and Mark Rushen is the Autistic Co-Chair of the NAPB. This is subject to review at an autism coproduction workshop run by the National Autistic Society, scheduled for September 2019.</p> <p>The Partnership Board is supported by a wider Norfolk Autism Partnership Group, the membership of which is open to everyone. There are 87 members of this group and people are welcome to join at any time.</p>

Topic	NAPG Minutes
Question 7	NAS West Norfolk never seem to receive any minutes, please ensure we do receive minutes and that our points are minuted together with your responses thank you. NAS West Norfolk 29 th July 2019
Answer 7	The NAPG is an open forum for the public. A verbal update on the work of the Partnership Board is given at the meeting by the NAPB Autistic Co-Chair along with details of any workshops held in the time between meetings.

	<p>Historically minutes of NAPG meetings have not been taken, but notes were taken at the last NAPG meeting on 14th May 2019 to facilitate future NAPGs. We suggest the following items are developed to promote good communications:</p> <ul style="list-style-type: none"> • A written update to the NAPG to share the work of the NAPB, based on the last NAPB meeting. • A <i>You said, We did</i> item, to share NAPB achievements developing from comments raised at the NAPG and other autism-related conversations. • <i>NAPG Questions</i>, to share the questions asked and the answers provided at or through the NAPG and other autism conversations. <p>These will be distributed to all NAPG members and added to the NAPB website.</p>
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Topic	Autism Strategy “My Autism, Our Lives, Our Norfolk”
Question 6	<p>NAS West Norfolk were recently told that NCC are engaging with autistic people about the adult social services charges through something called a new strategy ‘my autism our voice our Norfolk’. We have NEVER heard of this strategy and we would like that minuted very clearly please . What is it and who wrote it?</p> <p>Mr Borrett told full council on 22/7 that it was untrue that NAS did not know about this strategy which is deeply disturbing.</p> <p>We have asked all of our members and only 1 person in 400 members had ever heard of this strategy here in the West.</p> <p>we understand on the 5/8 the autism strategy is to be discussed by Cllr Bill Borrett in Council. What exactly is he going to be saying please. NAS West Norfolk 29th July 2019.</p>
Answer 6	<p>The autism strategy <i>My Autism, Our Lives, Our Norfolk</i> was distributed to the NAPG, including NAS West Norfolk, via the mailing list on 28^h March 2019. ASSD Autism did not receive any “bounce-backs” or “failure to deliver” notices from this email account following distribution to indicate that the email was not received or there was a problem with the delivery.</p> <p>Additionally, the autism commissioner visited representatives from NAS West Norfolk on 28th February 2019 and 5th June 2019. During these visits the latest draft of the autism strategy was shared with NAS representatives and discussions were had about day services, education and blue badges. Updates and changes were made to the autism strategy as a direct result of these meetings.</p>

	<p>The NAPB hopes this demonstrates our willingness to work with NAS West Norfolk in creating the autism strategy.</p> <p>Cllr Bill Borrett is the chair of the Health and Wellbeing Board (H&WB) that provides the governance for the NAPB. The autism strategy was approved at the Health and Wellbeing Board on 10th July 2019. On 5th August 2019 the autism strategy will be presented to Council Cabinet with recommendations. These recommendations are: to approve the strategy; to ask for all members to champion and implement the strategy and its priority work within their own constituencies; and for all cabinet members to complete the autism e-learning training and campaign to increase its uptake across Norfolk.</p>
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Topic	NCC Charging Policy
<p>Question</p> <p>5</p>	<p>Who exactly are the council engaging with about these adult social services charges please? Where, when, why does no one in the west know anything about any of this because certainly no one has engaged with us about anything.</p> <p>The situation over adult social services charges is reaching cabinet level with many discussions underway. As far as we know you have not engaged in this critical situation at all, nor engaged with anyone who is , in terms of how this effects autistic people generally in Norfolk. NAS West Norfolk 29th July 2019</p>
<p>Answer</p> <p>5</p>	<p>In November 2018 letters were written to everyone in receipt of a local authority service who would be affected by the Minimum Income Guarantee (MIG), as well as those who are in receipt of Personal Independent Payments (PIP) and receiving enhanced daily rate. In cases where it was recorded that a service user had a named contact for financial affairs, the named contact was written to on the service users' behalf. Those identified to have learning difficulties were sent an easy read version.</p> <p>Everyone who was written to had received a financial assessment as they were in receipt of a service. The letters advised if service users wished for a financial assessment to contact the Financial Assessments Team using details provided.</p> <p>The letter advised that Norfolk County Council (NCC) was considering changes in line with the MIG set by the Department of Health and asked for people's views. Service users and those named as their contact for financial affairs were given four weeks to respond from the date of the letter. The consultation told Norfolk County Council that people wanted support to manage budgeting, support to claim any disability rate expenditure and wanted a staged implementation to introduce the MIG. Following this, the decision then went to council on 11th Feb who agreed the change. In response to the consultation, the</p>

	<p>money support service is in place to help people with budgeting, advice to manage debt and to identify any other relevant and necessary extra expenditure that is related to their disability.</p> <p>The Department of Health (DoH) have set the MIG as follows: 18 years to 24 years old - £132.45 25 years old to pension age - £151.45 Above pension age - £189.</p> <p>Before July 2019, NCC MIG was set at £189.00 for all age groups. From 22nd July 2019 the “Above pension age” rate remains at the DoH MIG level of £189.00. NCC set the rate for “18 years to 24 years” and “25 years to pension age” to £165.00.</p> <p>From April 2020 all ages will be aligned to the DoH MIG rates, ie. 18 years to 24 years £132.45, 25 years to pension age £151.45 and above pension age £189.00.</p>
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Topic	SEN Process
Question 4	Does Norfolk County Council insist on a medical certificate “evidencing” SEN and if so why? NAPG 14 th May 2019 meeting.
Answer 4	<p>If a parent states that their child has an autism diagnosis, we would request evidence of this before we could write it in to a plan (as set out by BELOS – further education network), or NCC would consult with a school for which a specific diagnosis is required as an entry requirement e.g. The Wherry – ASD diagnosis.</p> <p>We do not ask for a medical certificate stating the child has a Special Educational Need (SEN).</p>

Topic	Children’s transition between secondary to high school provision
Question 3	Why is NCC not providing enough support to children transitioning from primary to secondary education? NAPG 14 th May 2019 meeting
Answer 3	Transitioning from Primary to Secondary education is the responsibility of schools. Where appropriate, Norfolk County Council will work with a child’s family and partners such as schools to put in place person-centred transition plans as part of their Education Health and Care Plan (EHCP). The support provided needs to be pitched at the right level for each individual child.

Topic	Capital Investment for new schools
Question 2	Councillors advised the new schools would cost £150m and that this budget had been agreed, is this correct? NAPG 14 th May 2019 meeting
Answer 2	Capital investment has been made of £120 million. This figure has been agreed and shared by councillors.

Topic	Further education autism provision for students 18+
Question 1	In the west we have NO further education autism provision for students 18+ who have autism and moderate to more severe learning disabilities since Plaxtole house was closed. This is creating huge numbers of young adults being placed in full time day care who really shouldn't be there. They are entitled to continue in appropriate education attaining vocational qualifications such as ASDAN which would assist them into an independence pathway towards supported voluntary work in the future. Instead they are written off as NEETS from 18. Our guys often need to be in a structured and productive environment and now aren't, due to a lack of educational provision in the west. Simply not good enough - is leading to poor mental health caused by frustration and resulting in self-harming and challenging behaviour and crisis due to wrong provision. Something has got to change urgently. NAS West Norfolk 13 th May 2019
Answer 1	Thank you for voicing your concerns. We will bring them to the Education Working Group to investigate further and discuss.

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