

**Minutes of the  
Norfolk All Age Autism Partnership Board (AAPB)**

**Held on: Monday 30 April 2018, 10:00 – 12:30**

**Venue: The Green Britain Centre, Turbine Way, Swaffham, Norfolk,  
PE37 7HT.**

**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>
James Bullion	Co-chair of NAPB & Executive Director of Adult Social Services (NCC)
Clare Smith	Co-chair of NAPB & NAAN (Norfolk Autism/Asperger's Network)
Rebecca Hird	Business Support Officer, Norfolk County Council (Minutes)
Michael Bateman	Head of Education High Needs SEND Service (NCC)
Sharon Brooks	Chief Officer, Carers' Council
Dr Melanie Bruce	Norfolk Community Health & Care NHS Trust
Jared Carpenter	Autistic Adult
Toni Collinson	Norfolk Constabulary
Joanna Corbyn	Parent Carer
Alison Furness	Family Voice
Lee Gibbons	ASD Helping Hands
Lauren Lonergan	Young Autistic Person
Lisa Lonergan	Parent Carer
Tracy Mclean	Great Yarmouth Clinical Commissioning Group - Children
Mark Rushen	Autistic Adult
Alexandra Smith	Young Autistic Person
Zandrea Stewart	Assistant Director – Learning Disabilities and Autism, Adult Social Services (NCC)
Steph Tuvey	Healthwatch
Carolyn Watts	Public Health (NCC)
Kim Woodrow	Parent Carer

<b>Apologies Received</b>	<b>Organisation and or Role</b>
Alan Hunter	NCHC Provider
Sue Medley	NSFT
Sue Bridges	NSFT
Dr Catherine Haig	Asperger Service Norfolk
Jocelyn Pike	South Norfolk CCG

Agenda Item 1	Welcome and Introduction	Action and Due Date
1.1	<p>Clare Smith and James Bullion welcomed everyone to the meeting and stated that they were pleased to be having a meeting to progress the autism agenda in partnership</p> <p>Clare Smith said that Norfolk County Council had recognised a year ago that it had lost the goodwill of a large part of the autism community, but that this Board could be an opportunity to do something constructive to improve the lives of autistic people and their families.</p> <p>James Bullion said that he recognises that we all need to do more to support people with autism and that the main thing is having an honest conversation about what has not worked in the past and focus on constructive intention.</p>	
1.2	Apologies were received from Alan Hunter NCHC provider, Sue Medley NSFT, Sue Bridges NSFT, Dr Catherine Haig Asperger Service Norfolk & Jocelyn Pike, South Norfolk CCG	
1.3	Introductions were made around the room.	
1.4	<p>The draft code of conduct was approved by consensus.</p> <p><b><i>All members voted in agreement to approve the code of conduct for Norfolk Autism Partnership Board meetings.</i></b></p>	

Agenda Item 2	Terms of Reference	Action and Due Date
2.1	The draft terms of reference were reviewed page by page and agreed with the following discussions and amendments.	
2.2	<p>Section 1. Purpose of Board</p> <p><b><i>All voted in agreement</i></b></p>	
2.3	<p>Section 2. Strategic Objectives.</p> <p><b><i>All voted in agreement</i></b></p>	
2.4	Section 3. Structure and Governance – this section has been divided into sub headings as follows:	
2.4.1	<p>Norfolk Autism Partnership Board (NAPB).</p> <p><b><i>All voted in agreement</i></b></p>	
2.4.2	<p>Working groups.</p> <p><b><i>All voted in agreement.</i></b></p>	

	Clare Smith highlighted the need for people with autism to volunteer to be part of these working groups and explained the purpose of working groups.	
2.4.3	<p>Norfolk Autistic Partnership Group (NAPG)</p> <p><b>All voted in agreement.</b></p> <p>Clare Smith explained the purpose of the group which will be made up by an informal membership of people who have autism and their families and carers or who work or volunteer in relevant fields. This group will feed into the partnership board.</p> <p><b>The continuation of the Norfolk Autism Partnership Group (NAPG) was agreed</b></p> <p>Zandrea Stewart shared the slide showing the indicative governance diagram. James requested adding the carers council to this.</p> <p><b>All voted in agreement with this addition.</b></p>	
2.5	<p>Section 4. Norfolk Autistic Partnership Board meeting arrangements.</p> <p><b>All voted in agreement.</b></p> <p>A discussion was started regarding future venues for the NAPB and it was agreed to pick this up at the end of the meeting.</p> <p>Clare Smith clarified that the final bullet point (about ‘concerns’) is an addition to the ToR agreed by the last (informal) NAPB meeting and was included by Zandrea Stewart. She added that most APBs have processes for dealing with complaints and that this is a reasonable one.</p> <p>Members voted to approve the addition.</p>	
2.6	<p>Section 5. Responsibilities of members.</p> <p><b>All voted in agreement.</b></p> <p>Members must attend at least three of the four annual meetings.</p> <p><b>All voted in agreement.</b></p>	
	<b>Action:</b> Clare Smith will share wording with Zandrea Stewart to be added to the Terms of Reference.	Clare Smith & Zandrea Stewart
2.7	<p>Section 6. Membership</p> <p>Mark Rushen highlighted that some changes have been made to the terms of reference but weren't declared. James Bullion and Clare Smith apologised for this and Zandrea Stewart explained a change has been made to the timeframe for the post of co-chairs and co-vice-chairs and NAPB members from 1 year to 2 years.</p>	

	<b><i>All voted in agreement with this section.</i></b>	
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<b>Agenda Item 3</b>	<b>Membership</b>	<b>Action and Due Date</b>
3.1	<p>Clare Smith asked for nominations for the election of vice co-chairs.</p> <p>James Bullion nominated Zandrea Stewart as his vice co-chair. Seconded by Clare Smith.</p> <p>Clare Smith nominated Mark Rushen for her vice co-chair. Seconded by Lee Gibbons.</p> <p><b><i>All voted in agreement with these positions.</i></b></p>	
3.2	The board reviewed Appendix 1 - Membership of NAPB.	
3.2.1	<p>As no-one had stood for the 'older autistic person (aged 65 or older)' seats, Clare Smith suggested changing the age range here to '(aged 55 or older)' and changing the age range for 'Autistic adults (aged 25-64)' to 'Autistic adults (aged 25-54).</p> <p><b><i>All voted in agreement to change autistic older person aged 55 or older and autistic adult 25-54.</i></b></p> <p>James Bullion suggested a discussion at Norfolk Older People's Partnership Board to seek some members to fill the vacancies for older person with autism.</p>	
	<b>Action:</b> Zandrea Stewart will take a discussion forward with the Norfolk Older People's Partnership Board.	Zandrea Stewart
3.2.2	CAMHS – Tracy Mclean advised CAMHS are redesigning services so suggested who the nominated representative would be was put on hold for a month.	
	<b>Action</b> for Tracy Mclean to update the board.	Tracey Mclean
3.2.3	Dr Melanie Bruce queried whether NCHC membership should consist of representation from child and adult services? It was agreed to have one person for consistency and the other as a deputy.	
3.2.4	Zandrea Stewart advised the recent appointment of a full time, permanent Integrated Autism Commissioner that will lead on the work with NCC who will attend the NAPB	
3.2.5	Zandrea Stewart advised that in identifying other members we needed to consider the whole age range and spectrum of autism both on the board and working groups. Joanna Corbyn suggested the Hamlet Centre and they cover adult and children.	

	<p>Lauren Lonergan suggested Sunbeams in Great Yarmouth.</p> <p>Alison Furness suggested raising at the Voluntary Sector Forum which consists of 13 different voluntary sector providers that are Norfolk-wide and covers services to a range of ages. Mark Rushen suggested that we do not fill the spaces yet and wait until we know what we need.</p>	
3.2.6	<p>Steph Tuvey provided a quick update on Healthwatch, who are the independent national champion for people who use health and social care services. Norfolk Healthwatch is doing a special project this year about autism. Voted whether they would be full members instead of having observer only status.</p> <p><b><i>All voted in agreement with this proposal.</i></b></p>	
3.2.7	<p>Norfolk Constabulary membership is observer-only status and the Board was asked to upgrade their membership to full voting status.</p> <p><b><i>All voted in agreement with this proposal.</i></b></p>	
3.2.8	<p><b><i>Following the above all members voted in agreement with Appendix 1 – Membership of NAPB.</i></b></p>	
3.3	<p>Clare Smith shared with the board some expressions of interest to join NAPB:</p> <p>x2 expressions as Autistic Adult members</p> <p>x3 expressions as Family member/carer. Clare Smith asked the board if they would like to vote now on election of members but Zandrea Stewart suggested people needed time to consider.</p> <p><b><i>NAPB members agreed to postpone voting until after the meeting. Clare will circulate details and collate votes before the next ANAPB meeting. She will also advise members of the outcome ASAP.</i></b></p>	

Agenda Item 4	Reports	Action and Due Date
4.1	Zandrea Stewart provided an overview of the work starting to take place and support required to go forward.	
4.1.1	a) Norfolk Autism Partnership Group (NAPG) and wider engagement with the autism community. Development of an engagement tool for the wider autism community to share their life experiences	

	<p>based around the priorities of the National Autism Strategy. Some work has started, and we would like members of the APB to contribute to its development and pilot, so it is fit for purpose.</p> <p>To include children and parents, adults and carers across the spectrum of need. The tool will need to be in a range of formats to enable as many people as possible to provide the feedback.</p> <p>The information will help the ANAPB to identify some of the priorities in the future work planning.</p>	
4.1.2	<p>b) Joint Strategic Needs Assessment (JSNA) – across Health and Social Care</p> <p>Norfolk doesn't have a full all age JSNA – in addition to a survey, public health has to develop an all age JSNA and participate in the engagement tool.</p> <p>Carolyn Watts updated that a lot of work is being done by Norfolk's Department of Public Health, waiting on engagement bit and looking at late Summer to publish. A draft of this document can be shared with the group.</p>	
	<p><b>Action:</b> Carolyn Watts will share Public Health's document recording autism with the NAPB for Zandrea Stewart. Zandrea Stewart to circulate with the board.</p> <p><b>Action:</b> Copy of document to be included at the next meeting.</p>	<p>Carolyn Watts &amp; Zandrea Stewart</p> <p>Next meeting</p>
4.1.3	<p>c) Data Collection</p> <p>To develop a better understanding of what data is being collected on identifying people with autism across the organisations and departments to help inform our future planning.</p> <p>Currently there is little understanding of the number of people with autism accessing services because it is not recorded.</p> <p>Zandrea Stewart's intention is to begin to collect the information and have a spreadsheet of the numbers using social care or who come into contact with the police or young people in receipt of EHCPs for example. Also identify the gaps. Mark Rushen started a discussion about the difficulty accessing autism diagnosis via GPs, which is widespread throughout Norfolk. Several autistic members echoed what he said, saying that many GPs don't know how/where to refer people. Tracy Mclean agreed to take this back to Norfolk CCGs for action.</p> <p>Michael Bateman advised in Education we are now data sharing, making autism a primary need.</p> <p>Board agreed that the collection of information was important.</p>	

	<p><b>Action:</b> To identify if Health providers, Social Care, Education and CJS/Police currently collect information on autism. GPs and Housing were also mentioned.</p> <p>Data collected and shared would not identify individual people.</p>	
4.1.4	<p>d) Autism Training for NCC &amp; NHS Staff (workforce training)</p> <p>Zandrea Stewart said NCC has completed a review of training about autism across their services. Clare Smith asked for a copy to be shared with the NAPB.</p> <p>Zandrea Stewart added that currently there is no autism workforce plan for the NHS/council partnership.</p> <p>NCC's plan is to provide tools including videos and eLearning modules to raise awareness among staff generally, to give more training to some individuals to create 'champions' within adult social care and to provide 'tiered' training for adult social care assessors.</p> <p>NCC wants to include autistic people to help develop this work and to deliver training once it's ready.</p> <p>James Bullion stressed the importance of everyone being aware of autism. Jared Carpenter expressed his surprise that NCC and Norfolk NHS organisations do not already provide such training. Mark Rushen said the latest Autism Act Statutory Update (2018) refers specifically to the need for workforce training and he endorsed developments in Norfolk.</p> <p>All agreed such training should include the NHS in Norfolk. Clare Smith mentioned NSFT which has developed a one-day training course suitable for staff as well as an eLearning module for autism awareness.</p> <p>Zandrea Stewart said the aim will be to have a multi-agency workforce programme where each organisation shares their plans.</p>	
	<p><b>Action:</b> Plans to be shared with nominated leads of NAPB.</p>	
4.1.5	<p>e) Children's Diagnostic Pathway</p> <p>Tracy Mclean provided an update: an extra £250,000 was invested in children's diagnosis to reduce waiting</p>	

	<p>times from two to one year maximum. This should be achieved by June 2018.</p> <p>Extra staff have been appointed and a pre-assessment programme to support families who are waiting for diagnosis has been started.</p> <p>The long-term aim is to reduce waiting times to a maximum of 18 weeks or less.</p> <p>Kim Woodrow said families like hers are having to fight their GP – often for months - to be referred. Other parents echoed this. Steph Tuvey said the failure of Norfolk GPs to refer people seeking such diagnoses, or resisting such requests, seems to be common across Norfolk. Tracy Mclean said CCGs were unaware of this.</p>	
	<p><b>Action:</b> This will be fed back by Dr Melanie Bruce and Tracy Mclean to NHS commissioners and providers with the aim of finding a way to inform all GPs about referral pathways.</p> <p>Clare Smith asked for a copy of the current pathway.</p> <p><b>Action:</b> Tracy Mclean will provide a copy to share with the board.</p>	Dr Melanie Bruce & Tracy Mclean
4.1.6	<p>f) Adult Diagnostic Pathway</p> <p>Zandrea Stewart reported that the JSCC (a committee of Norfolk’s five CCGs) has agreed to review future service models because of ‘capacity restraints’ and because the only existing service is the ‘Asperger Service Norfolk’, rather than a spectrum-wide diagnostic service.</p> <p>Even dealing only with ‘possible Asperger’ requests the service is struggling to cope and waiting times can sometimes be more than two years.</p> <p>Clare Smith had asked for a copy of the diagnostic pathway and was initially refused: she has therefore put in an FOI request to obtain it. Meanwhile, Zandrea Stewart obtained a document she was told was the adult diagnostic pathway. Clare Smith showed members the document – a one-page schematic. She said it is not a NICE-compliant diagnostic pathway.</p> <p>James Bullion added that he expects this Board to see current and future pathways and that they should be publicly available.</p>	
	<p><b>Action:</b> The relevant NHS providers and commissioners will provide a copy of the adult or Asperger’s diagnostic pathway to Zandrea Stewart for sharing with the NAPB before the next meeting of the NAPB.</p>	



4.1.7	g) National picture was postponed until next time, due to time constraints.	
4.1.8	<p>h) Autism Self-assessment 2018.</p> <p>Zandrea Stewart explained the Autism Self-assessment exercise: every couple of years, the government asks local health and social care services to assess what they provide so that the National Autism Strategy can be better implemented. The next is due to be published in early summer.</p> <p>Zandrea Stewart advised she would like this group to have sight of this assessment and contribute to its completion before formal sign off by the Health &amp; Wellbeing Board.</p> <p>Clare Smith said the last Norfolk self-assessment was considered by many within the autism community to have painted a much rosier picture than was truthful. She hopes this one will be more accurate.</p> <p>Zandrea Stewart advised it should be out by the next meeting in July.</p>	
4.2	<p>Michael Bateman provided a SEND update</p> <p>Sharing SEND leadership strategic priorities 2017-2020 for all special educational needs.</p> <p>Mark Rushen queried whether cluster funding is stopping? Michael advised yes there are some changes to funding. Schools provide the first £6000 then NCC fund additional funds from the central budget.</p>	

<b>Agenda Item 5</b>	<b>Working Groups</b>	<b>Action and Due Date</b>
5.1	James Bullion suggested that in view of the strong views expressed by members, an additional working group should be brought forward as a priority group – ‘diagnosis pathways’. The Board agreed so now four working groups.	
5.1.1	<p>a) Engagement with people: in particular developing the engagement tool.</p> <p>Expressions of interest were noted.</p> <p>Voted and agreed</p> <p>Following the meeting Kerry Cooper was nominated to take part in the group.</p>	

5.1.2	<p>b) Data Collection</p> <p>Expressions of interest were noted.</p> <p>Voted and agreed</p> <p>Following the meeting Lea West was nominated to take part in the group.</p>	
	<b>Action:</b> Identify organisations.	
5.1.3	<p>c) Workforce Development and Training</p> <p>Expressions of interest were noted.</p> <p>Voted and agreed</p>	
5.1.4	<p>d) Adult's and Children's Diagnostic Pathway</p> <p>Expressions of interest were noted.</p> <p>Tracy suggested a child lead being Mark Rushen and adult lead being Clare Smith.</p> <p>Following the meeting Kim Woodrow expressed an interest in being involved in this group.</p>	
5.2	<p>All Groups</p> <p>Zandrea Stewart advised that some work is underway and will look at how best the working groups can be set up and will advise. We will shortly have the information back from the engagement exercise and the Autism Self-Assessment Framework. Clare Smith advised we will look to develop the other working groups.</p> <p>Zandrea Stewart advised that where some areas of work are underway representatives from the Board would participate.</p>	

Agenda Item 6	Any Other Business	Action and Due Date
6.1	Clare Smith suggested inviting Rt Hon Patricia Hewitt, Chair of Norfolk STP to a future meeting to address NAPB – <b><i>all members agreed. Dates to be offered once available</i></b>	Future meeting

Date, time and location of next meeting
It was suggested to offer a range of dates early July before the schools break up. It was agreed to do a poll with the option of a few dates and the offer of possible venues.