

Minutes of the Norfolk All Age Autism Partnership Board (NAPB)

Held on: Tuesday 28th May 2024, 11:00 – 1:00pm

Venue: Microsoft Teams

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	Norfolk Autism Partnership Co-ordinator / Operations Manager (ASD Helping Hands)
Trevor Key	Co-Chair
Adrian Grant	Co-Chair
Caron Ager	Commissioning Programme Manager Learning Disabilities and Autism
Claire Jones	Local Offer Manager - SEND Strategic Improvement and Partnerships, Children's Services
Joseph Jarvis	Autistic Adult
Rachel Gates	Senior Program Manager
Stephanie Summers	Clinical Psychologist and Clinical Lead for the Neurodevelopmental Service (NCHC)
Stephen Durrance	Autistic Adult
Tracey Walton	Autism Commissioning Manager (Norfolk County Council)
Karen Dures	Strategic Business Lead – Autism (Norfolk County Council)

Apologies Received	Organisation and or Role
Catherine Haig	Clinical Psychologist (Autism Service Norfolk)
Maria Kerretti	Speciality Advisor for learning disability and autism (Norfolk
	and Waveney Integrated Care Board)
Maxine Blocksidge	Senior Adviser SEND (Norfolk County Council)
Ryan Hardy	Autistic Person
Sharon Brooks	Carers Voice Norfolk and Waveney

Pre- Meeting Support	Action and Due Date
15 minutes was given to pre meeting support for those who required it.	

Agenda Item	Welcome, Introduction & Approval of minutes and action log	Action and Due Date
1.1	Board Members were asked to introduce themselves in the Teams chat function	
1.2	Welcome and introductions made. Communication prompts posted to the Teams Chat window, and their use explained. No reasonable adjustments were requested. Members reported no declaration of interest.	
	Minutes and action log approved by the Norfolk Autism Partnership Board (NAPB)	
	Code of Conduct to be monitored by Lee Gibbons	
1.3	Action: To keep in contact with Tracey Wooldridge regarding further updates to the Care, Education and treatment review (to be expected in the early 2024)	Lee Gibbons Ongoing
	Outcome: Ongoing	
1.4	Action: Seek a formal response regarding non-NICE Compliant Assessments	Claire Angel 09/07/2024
	Outcome: Request for Claire Angell to take action as this would sit better in her remit	
1.5	Action: To find timeframes out for Autistic representation on the LD & A Programme Board	Completed
	Outcome: NAP now has representation on the Learning Disability & Autism programme Board	
1.6	Action: To arrange a presentation on the purpose and structure of the LD & A Programme Board	Lee Gibbons 09/07/2024
	Outcome: Unable to secure an LD & A representative to carry over to next meeting.	

1.7	Action: To publish: -Introduction to a Social Care Conversation (2 pages long)	Completed
	-Guide to a Social Care Conversation (Longer document with space for notes)	
	Outcome: These documents are now published on the NAP website under the 'Autism Information section'	
1.8	Action: Circulate Draft All age autism strategy refresh to all board members.	Completed
	Outcome: Document circulated on the 16th April 2024	

Agenda Item 2	Diagnosis Waiting List Updates	Action and Due Date
2.1	 Adult Diagnosis (without a Learning Disability) Annual average referrals of 92 each month Total number of adults waiting 1041 Average of 17 assessment a month Waiting period breakdown: 0 people waiting longer than 200wks 11 waiting between 200-104 weeks 318 waiting between 104–52 weeks 541 waiting between 52-18 weeks 171 Less than 18 weeks 	
2.2	Adult Diagnosis (without a Learning Disability) Year on year comparison of total numbers waiting Jan 2020 – 486 Jan 2021 – 665 Jan 2022 – 915 Jan 2023 – 740 Jan 1029 – 1029 In Feb 2024, the total number of adults waiting assessment is 111.7% increase from Jan 2020.	

2.3 Adult Diagnosis (without a Learning Disability)

Year on Year comparison of demand for assessment

	Average monthly referrals	Total Referrals	% of change since previous year
2020	28	339	Not applicable
2021	49	584	75%
2022	79	950	61.20%
2023	90	1081	13.90%

2.4 Adult Diagnosis (without a Learning Disability)

- A total of 204 additional assessments commissioned through The Owl Centre and Mind Professional Ltd. The Owl is working with Autism Service Norfolk and Mind Professional is working with Children and Young People service.
- Commissioners continue conversations with procurement regarding re-engineering diagnostic pathways in line with procurement regulations, to commission the service from March 2025. Analysis began to look at the diagnostic feedback received through the Autism Strategy to identify what is important to people.
- There has been additional funding allocated to offer approximately 100 additional assessments for adults in addition to the 204 assessments already commissioned

2.5	 Question: When will these additional assessments start? MIND have just sent out letters to those who are eligible with details of the options available to them Owl centre is a currently working with Autism Service Norfolk. The Diagnosis and Support working group are finalising the wording on the letter to be sent, to make sure they are appropriate for autistic people., The aim is to begin sending these in batch from mid-June with an aim to complete the send out of letters by the end of this year. 	
2.6	PDA Update A shared understanding of Pathological Demand avoidance has been created by the Diagnosis and Support working group with he input from partners and diagnostic services.	
	Action: The Board are asked to agree to this shared understanding in principle, with a final copy of this document sent out after the meeting. Any objections to signing off this document need to be emailed to Tracey Walton (tracey.walton@norfolk.gov.uk) before the 30 th May.	NAPB Members 30/05/2024
	Action: Once fully agreed this document will be available on the NAP website with a link to the PDA Society	Lee Gibbons 09/07/2024
2.8	Question: Will PDA be included in the new service specification for the diagnostic service? Answer: PDA will not be named explicably, however as a profile of autism spectrum disorders it should be considered and assessed in all autism assessments	
2.9	Question: If an autistic person reads the document and notices similar behaviours in themselves, would they need to be/could they're assessed to look at this profile?	
	Answer: The person autism diagnosis would not be reassessed, but they would be encouraged to find other avenues of support and resources.	

2.10	Comments around the need to just be weary of creating a demand for something that we do not have the services or resources to currently support in Norfolk and the strain this may place on existing and additional services.				
2.11	Children and Young People				
	Due to ongoing contract negotiations with providers this information is currently unavailable.				
2.12	Children an	d Young Pe	ople		
	Year on year	ar comparis	on of total n	umbers wait	ing
	These figure	es for James	Paget Hospi	tal:	
	 Jan 2020 – 228 Jan 2021 – 428 Jan 2022 – 226 Jan 2023 – no data Jan 1029 – 1993 				
	people awai	ting assessn	nent is over 3	nildren and yo 330% higher t 23 figures no	han
2.13	Children an	d Young Pe	ople		
	Year on Yea	-	on of demar	nd for	
		Average monthly referrals	Total Referrals	% of change since previous year	
	2019	84	1008	Not applicable	
	2020	102	1224	+21.4%	
	2021	144	1728	+41.2%	
	2022	229	2748	+59.0%	
	2023	264	3168	+15.3%	

2.14 **Children and Young People New Priorities for action** During 2024/25 a redesign of the offer of support available to those who are likely to be neurodiverse. Medical diagnosis should be an option only within a successful needs-led, flexible education and care system that improves outcomes for children and young people and supports families to manage the diverse experiences of their children, improving resilience and reducing duplication on multiple professional teams. 2.15 **Children and Young People System Collaborative Programme** A formal programme and project team is being created to address the gaps in support and barriers to accessing it for children and families. Children and young people services intention is to provide holistic and integrated services. Shift the culture and understanding of neurodiversity and meet the needs of children and young people, focusing on things that help. Broadening the commissioned model for assessments could alleviate pressure on our existing NHS pathways. 2.16 Children and Young People PINS whole school approaches NHS England, has invited expressions of interest from local systems to access over £200,000 in external funding. This Partnership for Inclusion of Neurodiversity in Schools (PINS) programme will bring health and education and parent carers into 4 Waveney mainstream primary settings to: help shape whole school SEND provision. provide early interventions at a school level. upskill school staff. support strengthening of partnerships between schools and parent carers.

2.17	Children and Young People	
	Neurodiversity Digital Library	
	 ICB is working with parents and carers and Cambridgeshire Community Services to develop a Neurodiversity digital library. 	
	The plan is to publish this library later this year.	
2.18	Children and Young People	
	Provider framework to establish quality mark for Norfolk and Waveney	
	 ICB has launched a procurement to expand the number of providers who can assess children in Norfolk and Waveney. 	
	 Quality benchmark for our footprint and give greater confidence to education, primary and community care colleagues on the efficacy of independent assessments undertaken for families. 	
2.19	Question: What is the reason for the significant increase, especially from Jan '22 – Jan'24?	Lee Gibbons 09/07/2024
	As Clare Angell was not present at the meeting this question will be passed onto her to respond	
2.20	Question: Regarding PINS (Partnership for Inclusion of Neurodiversity in Schools) how does this become practicable and how is it going to function?	Lee Gibbons 09/07/2024
	Answer: As Clare Angell was not present at the meeting this question will be passed onto her to respond.	
	It can be assumed that this is a national project based on evidence and that there will be framework and guidance about its delivery.	
2.21	Question: Is it possible to show the waiting time for Children and Young People in a similar way to how we receive waiting times data regarding adults?	
	Answer: As Clare Angell was not present at the meeting this question will be passed onto her to respond.	
	Comments were made about the difficulty due to current reporting and contractual agreements between commissioners and providers.	

	Members have asked for general idea of the waiting periods so that the partnership board has some idea of the waiting times for Children and Young People.	
2.22	Question: Do the NHS waiting time targets apply to Children and Young People as they do Adults?	
	Answer: There was a consensus that they do. A link was posted in the chat regarding 6+ year assessments detailing their expected wait times. (Currently 4-5 years for 6+ / up to 3 years for Pre-Years)	
	There were comments that if the target was the same as adults, then something drastic needed to be done as the currently waiting times are far exceeding the targets.	

Agenda Item 3	Co-production of the Norfolk Autism Strategy Refresh Delivery Plan	Action and Due Date
3.1	Signing of the Strategy	
	These are steps that have been or are currently in the process of being taken to sign off the Norfolk All Age Autism Strategy Refresh 2024-2029.	
	 The NAPB members have signed of the strategy (30/04/2024) 	
	TW and KD have currently got endorsements and sign of from:	
	-The Prison service LD & A Programme Board	
	ICB Public Board (they have requested a 6 monthly update from the NAPB)	
	 The Strategy is due to go to Cabinet mid-July The Health and Well being Board are asked to: adopt the strategy ask that partner organisations work with the NAPB, by putting in place a yearly 	
	plan and report on progress Review the yearly plan and managehigh level issues and risks raised by theBoard.	

3.2	Proposal to put into place and monitor a yearly plan
	Partner Organisations (by 31 st Aug 2024 then annually)
	will provide a yearly plan that details the actions they will take to deliver the priorities of the strategy
	identify an owner for each action detailed in the plan.
	Action Owners (by 31 st August then bi-monthly)
	by 31 August 2024 for their assigned action complete the NAPB Monitoring template
	bi-monthly update the NAPB Monitoring template
	Strategy Group (Monthly until Oct '24 then Bi- Monthly)
	provide a yearly plan based on what organisations and owners provide
	meet bi-monthly to review the Owners' NAPB Monitoring templates and discuss any issues/risks to propose actions for the Board
	provide a bi-monthly year 1 progress report to the NAPB.
	NAPB (Bi-monthly and annually)
	put in place the strategy group that will be supported by Tracey and Karen
	sign off the Year 1 plan
	bi-monthly review the strategy groups progress report
	decide on any actions to overcome issues or risks raised and acknowledge actions completed and their impact.
3.3	The Autism Strategy Reference is due to meet on the 29/05/2024 to discuss how to launch the Norfolk All Age Autism Strategy Refresh 2024-2029.

3.4	Question: Will the General Election hinder/prevent any of the proposals with regards to signing off through the governance structures? Answer: The General Election should not have any effect on the proposed plans; however, we need to be mindful of the potential cabinet members cannot use the strategy to their advantage.	
3.5	We need sign up and endorsements from NSFT, due the action points and feedback we received around Mental Health provision for autistic people.	
	Question: Can the NAPB do anything to support this?	
	Answer: At the current time, but we may need to escalate this to the LD & A programme board if we come up against significant barriers.	
	A member of the board mentioned that it may be worth writing to the new Chief Executive of NSFT.	
3.6	Question: Is there a contingency plan in place in case this approach to monitoring the plan does not go accordingly?	
	Answer: If this was to happen the Autism Strategy Reference group would need to consider a variety of options to bring back to the NAPB.	
3.7	Ask of the Board: Does the Board agree the proposed process to deliver and monitor the strategy plan?	
	Agreement from the board members.	

Agend Item 4	Break	Action and Due Date
4.1	A ten-minute break was held	

Agenda Item 5	Learning Disability and Autism Programme Board information and update	Action and Due Date
5.1	Agenda Item moved to next meeting	Lee Gibbons
		09/07/2024

Agenda Item 6	Research Project Update	Action and Due Date.
6.1	KD provided us with an update and results from the Short term research project into Social care for Autistic adults.	
6.2	This was a short term research project supported by University of east Anglia, Norfolk County Council and the Norfolk & Waveney ICB Research Capability Funding (RCF).	
	RCF supports researchers to scope out research ideas, so that a bid can be made to the National Institute of Health and Care Research for a larger grant for longer-term research.	
6.3	 The project aimed to understand more about: the needs, wellbeing and quality of life of autistic adults in Norfolk how we can measure this to evaluate effectiveness of the Norfolk Autism Adult Support Service (the new short-term service for autistic adults with emerging social care needs). 	
6.4	There were three sections to the research project:	
	 Set up Autism Research group 5 autistic adults Met once a month from November 2023 to March 2024 Oversaw and supported development of the project Ensured an autism perspective. 	
	 Scope Review (Findings) There is very little research into short term and other services for autistic adults Some studies suggest positive impacts, but more research is needed There are some services similar to Norfolk's in other parts of the UK. There is potential to share learning, and to compare models There are many different quality of life measures, which vary in how accessible and meaningful they are for autistic people. 	
	Survey	
	 To find out about the needs, wellbeing and quality of life of autistic adults in Norfolk To test tools for measuring wellbeing 	

	• Curvey enemed in January and closed in	
	 Survey opened in January and closed in February 2024 	
	• 119 full responses.	
	110 Idil 100polises.	
6.5	We asked autistic people what outcomes they	
	would like a support service to provide	
	The top answers were:	
	Feeling in control of day-to-day life	
	Having a safety net when things are not OK	
	Having improved health and wellbeing	
6.6	We asked autistic people what might stop them	
0.0	from accessing a support service	
	3	
	The top answers were:	
	 Not knowing what might be involved 	
	Feeling anxious about using a support service	
	 Previous bad experiences of using services 	
6.7	Autistic poople were asked to complete a Warld	
0.7	Autistic people were asked to complete a World Health Organisation Standard Quality of Life	
	Measure	
	The scores are similar to those generally found for	
	autistic adults in the UK, but lower than for the	
	general population.	
	People also rated their quality of life using an	
	Autism Spectrum Quality of Life measure	
	In each area about half of people reported that they were experiencing notable challenges.	
	Only 27% of people were happy with their current	
	friendships.	
	•	
	We asked people for feedback on the 2 measures	
	Most people said they were easy to use, and felt the	
	questions were relevant, especially for the autism	
	measure.	
	A full Project will be available on the Norfolk Autism	
	Partnership Website	
	(Add link when available)	
6.8	Learning for the Norfolk Autism Adult Support	
	Service	
	We have shared what people told us is important to them, and they are leaking at	
	important to them, and they are looking at how they can use this information to develop	
	their service.	
6.9	Applying for a grant from the National Institute	
	for Health and Care Research to enable a longer-	
	term evaluation of the service	

	 The project showed that more research is needed into effective ways to support autistic adults to improve their wellbeing and prevent needs from increasing. The survey provided evidence of the kind of outcomes that will be important to evaluate, and the measures that can be used. We hope that providing research evidence about what works well (potentially also including evidence from other areas) will enable the service to expand and develop in future. 	
6.10	It was noted that while a responses of 119 was a good result this only reflects a small percentage of autistic people within Norfolk. Therefore, caution should be used if the commissioning of any services are a result fo these results. It was explained that the results of this research project would not be used to commission new services. As with all research projects it is often those with the greatest need that do not engage. For a larger research project this would need to be taken into consideration.	
6.11	Question: Will the data be presented differently in the report? Answer: The measures used are standard measures and therefore the data needs to be presented in a way that reflects this, if we stray too far it no longer becomes a standard measure and could hinder any cross-research projects or understanding of the data. The Autism Research group have worked on making the data and information as accessible as possible.	
6.12	Question: What is the likelihood of PDA affecting participation in autism-based surveys and research programs? Is there research into this? Answer: There was no specific brief to investigate this as part of the scope of the research project. Researcher to be asked if they came across anything in the scoping review.	
6.13	Question: Are there plans to share this information to a wider audience? Autism organisations? Autistica for example?	

		I
	Answer: At this current time there is no proposal to	
	share this data wider.	
6.14	Question: Who owns this research and data?	
	Answer: There is no definitive owner. The research	
	was funded by the Norfolk and Waveney RCF,	
	although it is better to look at this research as a	
	partnership as opposed to one organisation.	
6.15	Question: When the project report is published on	
	the Norfolk Autism Partnership website can it be	
	taken to other forums?	
	Answer: Yes, this research project can be taken to	
	local forums although it wouldn't be suitable to go to	
	national forums or originations.	
6.16	Question: When the project report is published on	
	the Norfolk Autism Partnership Board website can	
	people send comments regarding its content?	
	Answer: Yes, there is multiple ways for people to	
	contact the Norfolk Autism Partnership through the	
	website. There would not be a public comment	
	section in relation to this research project.	
6.17	There was a suggestion for a member to load this	
	research project on to the NCC Insights Library. This	
	is managed by Alex Cox and an email can be	
	provided if required.	
6.18	Ask of the Board: Can the project report be	
	published on the Norfolk Autism Partnership	
	website?	
	Agreement from the board members.	

Agenda Item 7	Any other business?	Action and Due Date.
7.1	No other business was raised	

Agenda Item 8	Close of Meeting	Action and Due Date.
8.1	Co-Chairs thank all participants for coming and notified everyone of the next meeting date.	

Date, time and location of next meeting

Tuesday 30th July 2024 11:00-13:00

Upcoming Meeting Dates

Tuesday 24 September 2024 Tuesday 26 November 2024 Tuesday 28 January 2025 Tuesday 25 March 2025

Tuesday 25 March 202 Tuesday 27 May 2025 Tuesday 29 July 2025

Tuesday 30 September 2025

Glossary

ANF Autism Norfolk Forum

ASD Autism Spectrum Disorder

CQC Care Quality Commission

ICB Integrated Care Board

FOI Freedom of Information

GDPR General Data Protection Regulations

LD & A Board Learning Disability and Autism Programme Board

LDP Learning Disability Partnership

LDPB Learning Disability Partnership Board

NAP Norfolk Autism Partnership

NAPB Norfolk Autism Partnership Board

NAS National Autistic Society

NCC Norfolk County Council

NCH&C Norfolk Community Health and Care

NSFT Norfolk and Suffolk Foundation Trust

SEND Special Educational Need and Disabilities

UEA University of East Anglia

WAW World Autism Week

WG Lead Working Group Lead