



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

**Held on: Tuesday 24<sup>th</sup> September 2024, 11:00 – 1:00pm**

**Venue: Microsoft Teams**

**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>
Lee Gibbons	Norfolk Autism Partnership Co-Ordinator
Joseph Jarvis	Autistic Adult
Stephen Durrance	Autistic Adult
Laura Edwards	Autistic Adult
Karen Dures	Strategic Business Lead – Autism (Norfolk County Council)
Wayne Neuman	Carers Voice Norfolk
Caroline Willaims	Healthwatch Norfolk
Andy Hudson	Head of Personalisation, Quality of Care for LD and Autism (Norfolk and Waveney ICB)
Tracey Walton	Autism Commissioning Manager (Norfolk County Council)
Claire Jones	Local Offer Manager - SEND Strategic Improvement and Partnerships (Children's Services)
Andrew O'connell	Senior Nurse – LeDeR (Norfolk and Waveney ICB)
Rebekah Muttitt	Children and Young people's Mental Health (Tier 2) (NSFT)
Caron Ager	Commissioning Programme Manager Learning Disabilities and Autism (Norfolk and Waveney ICB)

<b>Apologies Received</b>	<b>Organisation and or Role</b>
Jamie Tyson	Parent/Carer
Maria Karretti	Speciality Advisor for Learning Disability and Autism (ICB)
Tina Allen	Support Worker (Autism Service Norfolk)
Trevor Key	Co-Chair / Parent/Carer
Bethany Slaughter	Norfolk Police Mental Health Team Supervisor (Norfolk Constabulary)

<b>Guests</b>	<b>Organisation and or Role</b>
Colin Lang	Independent

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

<b>Agenda Item</b>	<b>Welcome, Introduction &amp; Approval of minutes and action log</b>	<b>Action and Due Date</b>
<b>1.1</b>	As both Co-Chairs were unable to attend the meeting. Lee Gibbons chaired on their behalf.	
<b>1.2</b>	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	
<b>1.3</b>	Partners were notified that an automatic transcript of the meeting would take place to ensure accuracy of minutes. There were no objections	
<b>1.4</b>	Action: To keep in contact with Tracey Wooldridge regarding further updates to the Care, Education and treatment review	On Hold To follow up for next meeting

<b>Agenda Item 2</b>	<b>Diagnosis Waiting List Updates</b>	<b>Action and Due Date</b>
<b>2.1</b>	<p>Adult Autism Diagnosis Service Update</p> <ul style="list-style-type: none"> <li>Referral data for adult autism diagnosis in Norfolk was presented. In August 2024, 74 new referrals were received, bringing the monthly annual average to 76 referrals.</li> <li>The service is currently completing 18 assessments per month, with 1,240 people waiting for an assessment. This represents a 2% increase from June 2024 data reported.</li> </ul> <p>Breakdown of waiting times was shared:</p> <ul style="list-style-type: none"> <li>10 people waiting between 104 and 200 weeks.</li> <li>585 people waiting between 52 and 104 weeks.</li> <li>480 people waiting between 18 and 52 weeks.</li> <li>165 people waiting for less than 18 weeks.</li> </ul>	

<p><b>2.2</b></p>	<p>LG raised concerns about the growing waiting lists and asked how the Right to Choose option impacts the waiting list numbers.</p> <p>CA shared that there had been a 77% increase in right-to-choose referrals from 2023 to 2024. This has contributed to reducing waiting times for those opting for the NHS service.</p> <p>There is an expectation of a 13% reduction in waiting lists by the end of the year, partly due to the uptake of Right to Choose.</p>	
<p><b>2.3</b></p>	<p>LG inquired about the possibility of extending these contracts with private providers to ensure ongoing availability.</p> <p>CA responded that Right to Choose has not currently impacted on private providers waiting times with no reports of the 18 weeks referral to treatment timeframes exceeded. There is no official end date of Right to Choose; contracts are checked and reviewed as invoices come in, and there is flexibility for GPs to refer to the private provider as long as the private provider has a valid contract currently in place with any ICB.</p>	
<p><b>2.4</b></p>	<p>LG asked if there was an end date for the Right to Choose scheme and if it would impact private providers' waiting times.</p> <p>CA responded that there is no official end date; contracts are reviewed as invoices come in, and there is flexibility to extend as long as the provider has a valid contract with any ICB.</p>	
<p><b>2.5</b></p>	<p><b>Children and Young People Diagnostic Data</b></p> <p>LG presented the diagnostic data for children and young people, received from Leanne Stelmaszczyk (replacing Claire Angel in the commissioning role).</p> <p><b>Norfolk Community Health and Care</b></p> <ul style="list-style-type: none"> <li>• In August 2024, 295 referrals were received for neurodevelopmental assessments (NDS service), with a total of 7,112 children and young people awaiting assessment.</li> </ul> <p>Current wait times:</p> <ul style="list-style-type: none"> <li>• <b>355</b> waiting between <b>200-104 weeks</b>.</li> <li>• <b>1,561</b> waiting between <b>104-52 weeks</b>.</li> <li>• <b>1,244</b> waiting between <b>52-18 weeks</b>.</li> <li>• <b>110</b> waiting for <b>less than 18 weeks</b>.</li> </ul>	

	<p><b>Newberry Clinic – James Paget University Hospital</b></p> <p>In August 2024 the Newberry clinic has:</p> <ul style="list-style-type: none"> <li>• 2223 children and young people waiting a neurodevelopmental assessment.</li> <li>• 893 CYP on Great Yarmouth and Waveney Assessment Group</li> <li>• Average 40 assessments each month</li> </ul> <p>Current Wait Times:</p> <ul style="list-style-type: none"> <li>• <b>664</b> waiting between <b>104-52 weeks</b>.</li> <li>• <b>1035</b> waiting between <b>52-18 weeks</b>.</li> <li>• <b>518</b> waiting for <b>less than 18 weeks</b>.</li> </ul>	
2.6	<p>LG queried the reported figure of 18 assessments per month, asking if this number was correct as it seemed low. (With regards to Norfolk Community and Health Care)</p> <p>LG stated he had gone back to Leanne Stelmaszczyk for clarification and would update the board once more accurate figures were provided.</p>	
2.7	Action: LG to clarify the assessment figure with Leanne Stelmaszczyk and update the board with the correct numbers.	<b>Lee Gibbons 26<sup>th</sup> November</b>

<b>Agenda Item 3</b>	<b>All-Age Autism Strategy Oversight group Update</b>	<b>Action and Due Date</b>
3.1	The All-Age Autism Strategy was approved for launch at the July meeting. A Strategy Oversight Group has been formed, which includes six autistic people and parent carers.	
3.2	<p>The role of the Autism Strategy Oversight Group is to:</p> <ul style="list-style-type: none"> <li>• deliver a Year One Plan in an autism friendly format</li> <li>• oversee the development and progress of the Year One Plan and highlight areas of concern</li> <li>• monitor and share progress</li> <li>• Support the reporting of progress to various boards such as this board (every other month), Integrated Care Board's Learning Disabilities and Autism Programme Board (quarterly), Health and Wellbeing Board (as requested)</li> </ul> <p>Support the reporting of progress to the general public through the partnership communications and its website (frequency to be agreed).</p>	

3.3	<p>Key upcoming dates include:</p> <ul style="list-style-type: none"> <li>• 10th September 2024: Autism Strategy Oversight Group established with first meeting taken place,</li> <li>• By 7<sup>th</sup> October 2024: Autism Strategy Oversight Group to sign off on the draft Year One Plan.</li> <li>• By 24th November 2024: Draft Year One place to be presented to the Norfolk Autism Partnership Board for sign-off.</li> <li>• By December 2024: The Year One Plan will be made publicly available on the Norfolk Autism Partnership Board website.</li> </ul>	
3.4	<b>Action: To present board with the draft year one plan</b>	<b>Strategy Oversight Group</b> <b>26<sup>th</sup> November</b>

Agenda Item 4	LeDeR Review	Action and Due Date
4.1	The LeDeR programme (Learning from Lives and Deaths – People with a Learning Disability and Autistic People) is reviewing deaths of individuals to identify service improvement opportunities.	
4.2	<p>Andrew O’Connell provided a summary of the 2023/24 annual report findings:</p> <ul style="list-style-type: none"> <li>• The median age of death for people with learning disabilities and autism in Norfolk is 62 years, now in line with the national figure.</li> <li>• Respiratory disease remains the leading cause of death, with aspiration pneumonia being the most common.</li> <li>• There has been a 29% increase in notifications to the LeDeR programme due to improved referral processes.</li> <li>• The programme is seeing fewer prescriptions of psychotropic medications, which is a positive trend.</li> <li>• The biggest cause of autistic people without a learning disability is Suicide, misadventure or accidental death, with Respiratory conditions being the seconded largest cause.</li> </ul>	
4.3	<p>The full report can be read at:  <a href="https://www.kcl.ac.uk/ioppn/assets/fans-dept/leder-2022-v2.0.pdf">https://www.kcl.ac.uk/ioppn/assets/fans-dept/leder-2022-v2.0.pdf</a></p>	

4.4	<p>TW raised concerns about the exclusion of individuals who are still awaiting an autism diagnosis from LeDeR reviews.</p> <p>Andrew O’Connell explained that current GDPR regulations prevent them from including individuals without a confirmed autism diagnosis. However, this issue has been raised nationally.</p> <p>LE also questioned whether individuals with a high probability of autism, but awaiting diagnosis, could be included. Andrew reiterated that legal barriers prevent this.</p>	
4.5	<b>Action:</b> Andrew O’connell to contact the NHS England regional team to explain why they are unable to include someone without a formal diagnosis in the LeDeR review	<b>Andrew O’connell</b> <b>26<sup>th</sup> November</b>
4.6	<b>Action:</b> Andrew O’connell to forward the 2023 LeDeR review when published. Expected November 2024	<b>Andrew O’connell</b> <b>Expected Nov</b>

Agenda Item 5	Break	Action and Due Date
5.1	<b>A ten-minute break was held</b>	

Agenda Item 6	Autism Centre Project	Action and Due Date.
6.1	Colin Lang provided an overview of the proposed Autism Centre for Norfolk, aimed primarily at supporting families with children and young people up to the age of 25.	
6.2	The project is driven by personal experiences. The centre aims to offer a safe space for families to engage in activities and access resources tailored to their needs.	
6.3	A 2-3 acre site on the edge of Poringland has been identified, and discussions are ongoing with the landowner regarding planning permission.	
6.4	The proposed building would feature soft play areas, sensory rooms, training spaces, and more.	
6.5	The project requires approximately £2 million in funding, and a capital appeal is expected once the charity status is confirmed.	

	<p>JJ asked how people could stay updated on the project's progress.</p> <p>CL confirmed that a website and social media would be created once the charity status is secured. He also encouraged anyone interested to volunteer and provide input</p>	
6.6	<p>LE raised concerns about including autistic adults in the planning phase</p> <p>Colin Lang reassured that input from both children and adults would be welcomed.</p>	
6.7	<p>Anyone wanting to be involved in the development or volunteering with the new project should email Colin on:</p> <p>colin.lang2@ntlworld.com</p>	
6.8	<p>It was also requested that the members of the NAPB talk to people about the project to raise awareness and drive-up support for the project.</p>	

Agenda Item 7	Any other business?	Action and Due Date.
7.1	<p><b>Clive Lewis (South Norwich MP)</b></p> <p>Clive Lewis contacted the Shoebox Café, to arrange to visit our Adult Social group. The group were uncomfortable with this and have asked specific questions around the motive of the visit and where and if publicity would be used.</p> <p>We are awaiting a reply from his office.</p>	
7.2	<p><b>Office and Police Crime Commissioner interest in joining the NAPB</b></p> <p>The NAPB and NLDP have been contacted by the Police and Crime Commissioners office to join the Partnership Boards. LG has emailed back to arrange a meeting to discuss this and provided copies of the Norfolk Autism Strategy.</p>	
7.3	<p><b>Police and Crime Commission Consultation</b></p> <p>The NAPB have been notified of the Police and Crime Commissioner consultation.</p> <p>The consultation runs until 5pm on the 1<sup>st</sup> of November 2024.</p> <p>Consultation link: <a href="http://www.norfolk-pcc.gov.uk/police-and-crime-plan/police-and-crime-plan-202529-consultation/">www.norfolk-pcc.gov.uk/police-and-crime-plan/police-and-crime-plan-202529-consultation/</a></p>	

<p><b>7.4</b></p>	<p><b>Increase in Involvement fees and new method of submitting claims.</b></p> <p>The NAPB have increased the rates of involvement fees:</p> <p>Under 1 hour - £13.00  Between 1 – 2 Hours: £17.00  Over 2 Hours: £24.00</p> <p>Claims should now be made on the online form:  <a href="https://www.norfolkautismpartnership.org.uk/involvement-claims/">https://www.norfolkautismpartnership.org.uk/involvement-claims/</a></p> <p>If there are any issues using this form, we will still accept paper copies that are emailed to <a href="mailto:contact@norfolkautismpartnership.org.uk">contact@norfolkautismpartnership.org.uk</a></p>	
<p><b>7.5</b></p>	<p><b>Terminology</b></p> <p>JJ shared insights from Autism Anglia, noting that their literature now refers to Autistic Spectrum Condition (ASC) instead of ASD. This raised the question of whether ASC could be adopted more broadly.</p> <p>LG acknowledged the point and highlighted the dilemma of aligning with the DSM-5 diagnostic manual, which still uses ASD, versus adopting more person-centred terminology. He opened the floor for discussion on whether a shift in language would be feasible or preferred.</p> <p>LE contributed, mentioning her personal preference for the term "diagnosis" and expressing discomfort with "disorder" due to its implications of abnormality. She emphasised the need for universal language, drawing parallels to scientific terminology.</p> <p>RM explained that ASD is still used in healthcare due to alignment with diagnostic manuals like the DSM-5 and ICD-11. She mentioned that people can choose how they identify, but the medical term remains "disorder" because it reflects a difference in functioning, not something that can be "cured."</p> <p>AH mentioned that the Integrated Care Board (ICB) uses ASC to align with local authorities, although some services still use ASD.</p> <p>CA confirmed that her daughter's assessment report still uses ASD for proper coding.</p> <p>The Norfolk All Age Autism Strategy does not give guidance on this part from the use of Autistic person as</p>	



	<p>this was the preferred terminology when carrying out the co-production of the strategy.</p> <p>The discussion ended with LG acknowledging that while the board prefers to use "autistic person," there is no formal stance on ASD vs ASC. LE concluded by highlighting the need to balance medical diagnosis with personal identity.</p>	
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<b>Agenda Item 8</b>	<b>Close of Meeting</b>	<b>Action and Due Date.</b>
8.1	Co-Chairs thank all participants for coming and notified every one of the next meeting date.	

<b>Date, time and location of next meeting</b>
<p><b>Tuesday 26<sup>th</sup> November 2024 11:00-13:00</b></p> <p><b>Upcoming Meeting Dates</b>  <b>Tuesday 28 January 2025</b>  <b>Tuesday 25 March 2025</b>  <b>Tuesday 27 May 2025</b>  <b>Tuesday 29 July 2025</b>  <b>Tuesday 30 September 2025</b></p>

## **Glossary**

<b>ANF</b>	<b>Autism Norfolk Forum</b>
<b>DSM-5</b>	<b>Diagnostic and Statistical Manual of Mental Disorders fifth edition</b>
<b>ASD</b>	<b>Autism Spectrum Disorder</b>
<b>CQC</b>	<b>Care Quality Commission</b>
<b>ICB</b>	<b>Integrated Care Board</b>
<b>ICD-11</b>	<b>International Classification of Diseases 11<sup>th</sup> Revision</b>
<b>FOI</b>	<b>Freedom of Information</b>
<b>GDPR</b>	<b>General Data Protection Regulations</b>
<b>LD &amp; A Board</b>	<b>Learning Disability and Autism Programme Board</b>
<b>LDP</b>	<b>Learning Disability Partnership</b>
<b>LDPB</b>	<b>Learning Disability Partnership Board</b>
<b>LeDeR</b>	<b>Learning from the lives and deaths of people with a learning disability and autistic people</b>
<b>NAP</b>	<b>Norfolk Autism Partnership</b>
<b>NAPB</b>	<b>Norfolk Autism Partnership Board</b>
<b>NAS</b>	<b>National Autistic Society</b>
<b>NCC</b>	<b>Norfolk County Council</b>
<b>NCH&amp;C</b>	<b>Norfolk Community Health and Care</b>
<b>NLDP</b>	<b>Norfolk Learning Disability Partnership</b>
<b>NSFT</b>	<b>Norfolk and Suffolk Foundation Trust</b>
<b>SEND</b>	<b>Special Educational Need and Disabilities</b>
<b>UEA</b>	<b>University of East Anglia</b>
<b>WAW</b>	<b>World Autism Week</b>
<b>WG Lead</b>	<b>Working Group Lead</b>
<b>ICB</b>	<b>Integrated Care Board</b>