



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

**Held on: Wednesday 31<sup>st</sup> January 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	Partnership Coordinator / Note Taker Voluntary Sector Representative, Autism Partnership Coordinator, ASD Helping Hands
Trevor Key	Co-Chair
Joseph Jarvis	Autistic Adult
Stephen Durrance	Autistic Adult
Adrian Grant	Co-Chair / Autistic Adult
Laura Edwards	Autistic Adult
Caroline Williams	Head of Engagement – Health Watch Norfolk
Stephanie Summers	Clinical Psychologist and Clinical Lead for the Neurodevelopmental Service (NCHC)
Sophie Little	Carers Voice
Tracey Walton	Autism Commissioning Manager (Norfolk County Council)
Alison Furniss	Family Voice
Jamie Tyson	Family Voice
Clare Angell	Head of Children, Young People & Maternity Services
Andrew Thain	Norfolk Police

<b>Apologies Received</b>	<b>Organisation and or Role</b>
Andy Hudson	Head of Personalisation, Quality of Care for LD and Autism
Catherine Haig	Clinical Psychologist (Autism Service Norfolk)
Karen Dures	Strategic Business Lead – Autism (Norfolk County Council)
Maxine Blocksidge	Senior SEND Advisor
Rachel Gates	Senior Programme Manager (Norfolk County Council)
Rebecca Crossley	Children and Young people's Senior Clinical Lead Mental Health, Learning Disabilities and Autism
Tina Allen	Support Worker (Autism Service Norfolk)

<b>Presenters</b>	<b>Organisation and or Role</b>
Andrew O'Connell	Senior Nurse- LeDer

<b>Guests</b>	<b>Organisation and or Role</b>
Joseph Royal	Neurodiversity Support Manager (HM Prison and Probation Service)
Emma Beales	Norfolk learning Disability Co-ordinator (ASD Helping Hands)
Gemma Peloe	Autism Advisor (ASD Helping Hands)

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

<b>Agenda Item</b>	<b>Welcome, Introduction &amp; Approval of minutes and action log</b>	<b>Action and Due Date</b>
1.1	Board Members were asked to introduce themselves in the Teams chat window	
1.2	<p>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.</p> <p>Minutes and action log approved by the Norfolk Autism Partnership Board (NAPB)</p> <p>Code of Conduct to be monitored by Lee Gibbons</p>	
1.3	<p><b>Action: Arrange for Pathological Demand Avoidance update</b></p> <p>Update provided by Stephanie Summers for NAPB Diagnosis Working Group: 9 January 2024. Few tweaks to the document required. Ask that the NAPB logo is used rather than all the individual logos. Training links to be added.</p> <p>Once agreed can be formally published.</p>	
1.4	<p><b>Action: Add information of Autism relevant organisations to the partnership's independent website</b></p> <p>Update: To be actioned in item 7</p>	
1.5	<p><b>Action: Rachel Gates to feedback to the NAPB on the request for Autistic people to join the LD&amp; A partnership Board.</b></p>	

	Update: Rachel Gates has escalated this to the chair of the LDA Board who has in turn escalated this Tricia D’Orsi. Acknowledgment that Autism needs to have its own forum. The LD & A board want to ensure they have things ‘right’ before inviting autistic representation to the LD and & Programme board.	
1.6	<b>Action: To keep in contact with Tracey Wooldridge regarding further updates to the Care, Education and treatment review</b>  Update: To continue communication for when there is an update available.	
1.7	<b>Action: The Norfolk Autism Partnership Board have been asked if they would like to join the Coalition for Change as an Organisation. A poll to be sent out to all members to vote on this.</b>  Update: Waiting for response from Autistic Members, planned to go ahead once their response has been obtained.	

<b>Agenda Item 2</b>	<b>Oversight Board Update</b>	<b>Action and Due Date</b>
1.1	No progress has been made since last Board meeting	
1.2	Will arrange one meeting per priority so that we can complete the Live Priority Document	
1.3	Aim to have this completed by next Board meeting to present to partners	
1.4	<b>Action</b> Organise meetings to focus on each priority	Lee Gibbons March ‘24
1.5	<b>Action</b> Complete Live Priority Document	Lee Gibbons March ‘24

<b>Agenda Item 3</b>	<b>Diagnostic Update (Diagnostic Data circulated before the meeting)</b>	<b>Action and Due Date</b>
3.1	<p><b>Adult Diagnosis (without a Learning Disability)</b></p> <ul style="list-style-type: none"> <li>• Annual average referrals of 91 each month</li> <li>• Total number of adults waiting 954 (48% increase since completion of the initiative work completed)</li> </ul> <p>Waiting period breakdown:</p> <ul style="list-style-type: none"> <li>• 12 waiting between 200-104 weeks (1 person waiting longer than 200wks)</li> <li>• 200 waiting between 104–52 weeks</li> </ul>	

	<ul style="list-style-type: none"> <li>• 496 waiting between 52-18 weeks</li> <li>• 246 waiting up to 18 weeks</li> </ul>	
3.2	<p>Continued high referral rates and low assessment outcomes there has been a 70% increase in people waiting for a diagnostic assessment.</p> <p>Commissioners have identified one of funding to:</p> <ul style="list-style-type: none"> <li>• Invest in reducing wait times</li> <li>• work with children and young people to provide an autism assessment for those transition to adult services</li> </ul> <p>Continued conversations around re-engineering the pathway in line with procurement regulations for March 2025</p>	
3.3	<p><b>Question</b></p> <p><b>Appreciate that offering early assessments to people waiting from April '23 is a good approach. Consideration needs to be given to the people offered early assessment already and for their reasons for not taking an assessment earlier to offer them another opportunity.</b></p> <p>This feedback was taken on board and will be reflected in the options paper.</p>	
3.4	<p><b>Question</b></p> <p><b>Is the recurring funding or one off?</b></p> <p>This funding is one off. The Board may wish to look at what funding is available for Norfolk and how we can influence elected individuals to improve the funding landscape for Autism assessments in Norfolk.</p>	
3.5	<p>A member of the board made comment about how important it is for the Norfolk Autism Partnership Board to be represented in various forum including the LD &amp; A Programme board to ensure that autistic peoples views and priorities are heard across all areas of the system providing support and healthcare for the autistic community in Norfolk.</p>	
3.6	<p><b>Children and Young People wait times.</b></p> <p><b>Norfolk Community and Health Trust (central and West)</b></p> <ul style="list-style-type: none"> <li>• 6250 children on the waiting list</li> <li>• Average of 264 referrals a month</li> <li>• Discharge 70</li> </ul> <p><b>James Paget Hospital</b></p> <ul style="list-style-type: none"> <li>• 3040 children on the waiting list</li> <li>• Average of 160 referrals a month</li> </ul>	

	<ul style="list-style-type: none"> <li>• Discharge 32</li> </ul> <p><i>Discharged does not mean they received a diagnosis but had an outcome meeting with the paediatrician.</i></p>	
3.7	<p>System collaborative of organisations including Norfolk County Council, ICB, NSFT and NCHC wish to work on a system approach for supporting our neurodivergent population.</p> <p>Funding for 2024/25 has been identified to support implementing a provider framework where individuals can be signposted to locally quality assured independent providers.</p> <p>Additional programme management capacity needed to accelerate this programme.</p> <p>Meeting held with NAPB members to revise data request for 2024 before formal contract variations can be enacted.</p> <p>300% increase in waiting times since 2019.</p>	
3.8	<p>Guidance on Parents/Carers paying for a private diagnosis has now been uploaded to the Improving Lives Website</p> <p><a href="https://improvinglivesnw.org.uk/our-work/healthier-communities/children-and-young-people/">https://improvinglivesnw.org.uk/our-work/healthier-communities/children-and-young-people/</a></p>	
3.9	<p>Discussion around the need to move from a clinical pathway to amore therapeutic and holistic viewpoint, where we base support and reasonable adjustments on need and not diagnosis basis.</p> <p>Needs to be understanding of the individual, their needs and the needs of the family. Should encompass Health, Social care and Education.</p> <p>There is no adult model that we can look at for therapeutic approach so needs to be fully designed.</p> <p>Acknowledgment that autistic experience barriers to accessing therapeutic services and providers also experience barrier in delivering due to financial and time constraints.</p>	
3.10	<p><b>Question</b></p> <p><b>Is there any data on the education placements or status of children &amp; young people on the waiting list.</b></p>	

	<p>There is no data currently as it is not collected.</p> <p>Comment- It seems that all support is pushed towards social care and Health, whereas a child or young person spends most of their time in an educational placement.</p> <p>Childrens experience depend very much on the school, their understanding and setting. Environmental factors, including the property the school uses have a large impact on what can be offered.</p> <p>Acknowledgement that some SENCO's are very keen and proactive but constrained by knowledge and funding.</p> <p>A 30% reduction in budget has had a large impact on the ability of the NHS to meet demand.</p>	
3.10	<p><b>Question</b></p> <p><b>How can the NAPB support in this?</b></p> <p>Continue to highlight the challenges across the system.</p> <p>NAPB to look at strengthening our position and how we can influence elected individuals and councillors to lobby central government arounds funding available for autism assessments and support.</p> <p>Compile anecdotal evidence of challenges and difficulties.</p> <p><i>(Healthwatch have provided feedback from the SEND event 22/11/23)</i></p>	

<b>Agenda Item 4</b>	<b>NAPB 2 Page Briefing</b>	<b>Action and Due Date</b>
4.1	Lee Gibbons represented the Two-page briefing for the NAPB and asked the board for agreement and sign off.	
4.2	<b>Action</b> Agreed in principle after grammar/formatting issues resolved	<b>Lee Gibbons</b> <b>07/02/2024</b>
4.3	<b>Action</b> To be electronically distributed to partners and uploaded to the website.	<b>NAPB</b> <b>26/03/2024</b>

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

Agenda Item 6	Introduction to LeDeR	Action and Due Date.
6.1	Andrew O'Connell provided an introduction on LeDeR (Learning from lives and deaths – People with a learning disability and autistic people).	
6.2	<p>LeDeR is a service improvement programme which aims to improve care, reduce health inequalities, and prevent premature mortality of people with a learning disability and people with autism by reviewing information about the health and social care support people received. This accomplished by:</p> <ol style="list-style-type: none"> <li>1. Delivering local service improvement, learning from LeDeR reviews about good quality care and areas requiring improvement.</li> <li>2. Driving local service improvements based on themes emerging from LeDeR reviews at a regional and national level.</li> <li>3. Influencing national service improvements via actions that respond to themes commonly arising from analysis of LeDeR reviews.</li> </ol>	
6.3	<p>Everyone with a learning disability and/or autism aged eighteen and above who dies is eligible for a LeDeR review. The definition of a learning disability is taken from the national LeDeR policy 2021.</p> <p>For an autistic person to be eligible for a LeDeR review, they must have had a confirmed diagnosis of autism recorded in their clinical records prior to their death.</p>	
6.4	LeDeR does not carry out reviews on children (under 18yrs) this is done through the Child Death Review Team.	
6.5	Referrals can be made to LeDeR by anyone. This take about 10 minutes and can be done through their website ( <a href="#">LeDeR website</a> )	
6.6	<p>Every person with a learning disability whose death is notified to LeDeR will have an <b>initial review</b> of the health and social care they received prior to their death.</p> <p>The reviewer with the support of our Local Quality Assurance Panel will determine where a <b>focussed</b></p>	

	<p><b>review</b> is required. A focussed review is a more in depth “deep dive” of a person’s care and support. Focused reviews will also be completed for:</p> <ul style="list-style-type: none"> <li>• Anyone from a Black, Asian or Minority Ethnic background.</li> <li>• Every adult with a diagnosis of Autism with no learning disability</li> <li>• Anyone who have been in contact with the criminal justice system in the last five years.</li> <li>• Anyone held under a section of the Mental Health Act in the last five years.</li> <li>• Anyone whose family request a focussed review, where there is agreement from the LeDeR team.</li> </ul>	
6.7	<p><b>Autism Reviews</b></p> <p>In the national report there were 36 deaths reviewed of Adult with Autism and No learning disability.</p> <ul style="list-style-type: none"> <li>• suicide, misadventure or accidental death -11</li> <li>• respiratory conditions -8</li> <li>• Cardiovascular and stroke related. Less than 5</li> <li>• Cancer – Less than 5</li> <li>• Other reasons – 8</li> </ul> <p>Split between 81% Autistic males and 19% Autistic females</p>	
6.8	<p><b>Autism and LD Reviews</b></p> <p>In the national report there were 178 deaths reviewed of Adult with Autism and a learning disability</p> <p>Respiratory conditions – 66  Cardiovascular conditions – 27  Cancer – 22  Covid-19 – 17  Stroke, cerebral haemorrhage or Embolism – 8</p> <p>Of these numbers 68% were males, 30% were female</p>	
6.9	<p><b>Question</b>  <b>Why has suicidal deaths been included in the accidental death category?</b></p> <p>It was explained that these are done using the coding of the ICD-10 which are led by the national team.</p>	



6.10	<p><b>Question</b>  <b>Without GP surgeries recording who it autistic, how can LeDeR ensure that they are accounting for all deaths of autistic people?</b></p> <p>Aware of the complications this presents but there is encouragement to use the responsible flag in patients records so this is notified across the system. Andre is due to speak to the Diagnosis and Support working group regarding this.</p>	
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<b>Agenda Item 7</b>	<b>Autism Directory</b>	<b>Action and Due Date.</b>
7.1	Lee Gibbons provided an overview of the plans for an Autism directory and asked the board to form a task and finish group to ensure this meets autistic peoples needs.	
7.2	Plan of 5 sessions (4 to design and build the directory / 1 to adjust to any feedback)	
7.3	<p><b>Action</b>  Invites to be sent out to the partnership members to see who would like to join the task and finish group)</p>	<p><b>Lee Gibbons</b>  <b>02/02/2024</b></p>

<b>Agenda Item 8</b>	<b>Making it Real Board Request</b>	<b>Action and Due Date.</b>
8.1	Request from 'Making It Real Board' for autistic representation.	
8.2	<p><b>Action</b>  To send round information again to Autistic members of the board, so they can register interest.,</p>	<p><b>Lee Gibbons</b>  <b>02/02/2024</b></p>

<b>Agenda Item 9</b>	<b>Any Other Business</b>	<b>Action and Due Date.</b>
9.1	<p><b>Dental Service Survey</b></p> <p>The ICB are asking groups to complete the long-term dental plan for Norfolk survey. Do the board wish to respond?</p> <p><b>Action</b>  To meet with co-chairs to discuss how we will facilitate this.</p>	<p><b>Lee Gibbons / Co-Chairs</b>  <b>21/02/2024</b></p>
9.2	<p><b>Signposting documents for adults</b></p> <p><b>Action</b>  Circulate the sign posting information to the partnership for feedback and sign of.</p>	<p><b>Lee Gibbons / NAPB members</b>  <b>21/02/2024</b></p>

Agenda Item 10	Close of Meeting	Action and Due Date.
10.1	Co-Chairs thank all participants for coming and notified everyone of the next meeting date.,	

Date, time and location of next meeting
<p>Tuesday 26<sup>th</sup> March 2024 11:00-13:00</p> <p><b>Upcoming Meeting Dates</b></p> <p>Tuesday 26 March 2024  Tuesday 28 May 2024  Tuesday 30 July 2024  Tuesday 24 September 2024  Tuesday 26 November 2024  Tuesday 28 January 2025  Tuesday 25 March 2025  Tuesday 27 May 2025  Tuesday 29 July 2025  Tuesday 30 September 2025</p>

## 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