

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

Held on: Tuesday 18 July 2023, 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 |
|-------------------|---|
| Trevor Key | Co-Chair |
| Lee Gibbons | Partnership Coordinator / Note Taker Voluntary Sector Representative, Autism Partnership Coordinator, ASD Helping Hands |
| Alison Furniss | Family Voice |
| Andrew Macey | Parent/Carer |
| Bethany Slaughter | Norfolk Police Mental Health Team Supervisor |
| Holly Purchase | Autistic Adult |
| Karen Dures | Strategic Business Lead – Autism (NCC) |
| Laura Edwards | Autistic Adult |
| Maxine Blocksidge | Senior Adviser SEND (NCC) |
| Paul Rout | Parent /Carer Chair of Governors Churchill Park |
| Rachel Gates | Senior Program Manager (ICB) |
| Rebakah Muttitt | Children and Young people's Mental Health (Tier 2) (NSFT) |
| Richard Peat | Parent/Carer |
| Sharon Brooks | Carers Voice for Norfolk & Waveney |
| Stephen Durrance | Autistic Adult |
| Tracey Walton | Autism Commissioning Manager (NCC) |
| Lucy Adcock | Norfolk learning Disability Partnership Co-ordinator |

| Apologies Received | Organisation and or Role |
|---------------------------|--|
| Adrian Grant | Co-Chair / Autistic Adult |
| Andy Hudson | Head of Personalisation, Quality of Care for LD and Autism |
| Caroline Williams | Head of Engagement – Health Watch Norfolk |
| Caron Ager | Commissioning Programme Manager Learning Disabilities |
| | and Autism (ICB) |
| Catherine Haig | Autism Service Norfolk |
| Claire Jones | Local Offer Manager – Family Help and SEND |
| Daniel Spooner | Norfolk County Council Childrens Services |
| Maria Karretti | Safeguarding Adults Clinical Advisor for Autism and |
| | Learning Disabilities |
| Rebecca Crossley | Children and Young people's Senior Clinical Lead Mental |
| | Health, Learning Disabilities and Autism |
| Stephanie Summers | Clinical Psychologist (NSFT) |
| Susan Willgoss | Service User Governor (NSFT) |

| Presenters | Organisation and or Role |
|-------------|--------------------------|
| Diane Smith | Talking Therapies (ICB) |

| | 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 | 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) | |
| 1.2 | Code of Conduct monitored by Lee Gibbons | |
| 1.3 | Action: Arrange for Pathological Demand Avoidance update A plan is in place. The diagnostic working group is looking at how to communicate the current statement and what training is going to be offered to accompany this. | TW / RM to discuss at next Diagnosis working group |
| 1.4 | Action: Rebecca Crossley to introduce Lee Gibbons to those who can present information on the ratification process and risks | Completed |

| | A letter has been received stating that the NHS will no longer ratify the diagnosis from private assessments, but there is communications being drawn up that parents/carers and private assessors know what is expected of an assessment. | |
|------|--|-------------------------------|
| 1.5 | Action: Add information of Autism relevant organisations to the partnership's independent website | LG – Currently placed on hold |
| | Lee Gibbons has asked the board to place this on hold while he looks at some other options to bring back to the board. Board agreement to place action on hold | |
| 1.6 | Action: To obtain information on the national position of Autism Diagnosis waiting times in Norfolk | Completed |
| | NHS digital have published Autism assessment waiting times. If required co-chairs to arrange a meeting with JY and TW to explain this data. | |
| 1.7 | Action: A task and Finish group is to be formed in respect to writing a statement from the Norfolk Autism Partnership concerning Autism assessment waiting times for adults. | LG |
| | Unsure of how board want to or if they do want to proceed with this. To discuss with co-chairs at next co-chairs meeting. | |
| 1.8 | Action: Begin to form the steering group by sending out an expression of interest email | Completed |
| | Expression of interest sent out on the 22/05/2023 | |
| 1.9 | Action: Update NAPB website with information regarding the Steering group and upload the approved TOR and R& R documents | Completed |
| | Documents corrected and uploaded top the NAPB website on the 22/05/2023 | |
| 1.10 | Action: To contact Coalition for Change to arrange a discussion with the Co-Chairs or invite to Board meeting/Steering group meeting | Completed |
| | LG held a meeting with Coalition for Change on 27/06/2023 regarding the Norfolk Autism Partnership and invited them to attend. They advised they are at capacity but would welcome the chance to work together if required in the future. | |
| 1.11 | Action: In response to query around easy read to produce the next slide deck alongside Autistic Members | Completed |

| | New slide decked was put together, no Autistic person input due to timeframes. No negative feedback regarding new designs. | |
|------|---|-----------|
| 1.12 | Action: To arrange meeting between co-chairs and Rachel Gates to discuss involving Autistic people in the LD & A Board Co-chairs and RG met on the 24/05/2023. Update provided in Item 3 | Completed |
| 1.13 | Action: Invite Kay Mason-Billig (Council leader) to the Norfolk Autism Partnership for an introduction to herself and our work Letter sent on behalf of the Co-chairs on the 25/05/2023, No reply yet. | Completed |

| Agenda Item 2 | LD & A Programme Board update | Action and Due Date |
|------------------|---|---------------------|
| 2.1 | Rachel Gates provided us with an update on the involvement of Autistic people in the LD & A programme board | |
| 2.2 | There is currently some work going on around strategic governance at Norfolk County Council overseen by Tricordant. They are focusing on the relationship between adult social care and ICB | |
| 2.3 | The LD & A Programme board form part of this scope | |
| 2.4 | Currently The LD & A board consider both Learning Disabilities and Autism and from a peer observation the issues around Autism seem to get lost in the conversation. | |
| 2.5 | Currently the LD & A Board are drafting terms of reference to support Autistic people to participate | |
| 2.6 | The LD & A board want reassurance that they can fit co-production in their meeting slot, which for Autism would be allocated to 60 minutes (1 hour) | |
| 2.7 | The LD & A Board want to focus on how they can separate the board effectively. This has been escalated in a working group involving Tricordant. | |
| 2.8 | SB concerned around how long people are going to be involved/invited for co-production. Better co production happens when people are involved from the beginning. Need to decide whether this is co-production or consulting? | |
| 2.9 | Action: Rachel Gates to go back to the LD & A Board and ask for an update on the progress of involving Autistic people on the Board. | RG 19/09/2023 |

| Agenda Item 3 | Updates on the Diagnostic waiting times | Action and Due Date |
|------------------|---|---------------------|
| 3.1 | Tracey Walton gave us an update on the diagnostic waiting times for Norfolk | |
| 3.2 | Adult wait times (as of May 2023) | |
| | Monthly average of 88. Average of 16.5 referrals each month | |
| | In March 2023 there 634 adults waiting for an assessment | |
| | Over the past 12 months there have been: | |
| | 1067 completed assessments. 200 by Autism Service Norfolk 867 by independent | |
| 3.3 | Waiting times for first appointment: | |
| | 36 waiting between 104-200 weeks. 202 waiting between 52 and 104 weeks. 154 waiting between 18-52 weeks. 242 waiting under 18 weeks. | |
| | It was noted that those waiting over 200 weeks was not a true reflection due to how the services measures waiting times for those that disengage then reengage | |
| 3.4 | Children and Young People wait times. | |
| | Norfolk Community and Health Trust (central and West) | |
| | As of May 2023 | |
| | 5496 children on the waiting list as of May2023 Average of 150 referrals month | |
| | Waiting times for first appointment: | |
| | 1996 waiting between 104-200 weeks. 810 waiting between 52 and 104 weeks. 1412 waiting between 18-52 weeks. 889 waiting under 18 weeks | |
| | | |

| James Paget Hospital | |
|---|--|
| 1137 children on the waiting list as of May2023 Average of 139 referrals month | |
| Waiting times for first appointment: | |
| 0 waiting between 104-200 weeks. 298 waiting between 52 and 104 weeks. 392 waiting between 18-52 weeks. 447 waiting under 18 weeks | |
| CYP NDD data is shared of which 20% are predicted as needing an autism assessment | |
| | |

| Agenda Item 4 | Co-Production opportunities Part 1 | Action and Due Date |
|------------------|---|---------------------|
| 4.1 | KD and TW gave us an overview of the Co-production and tools that will be used in the coming opportunities: | |
| | Co-production and engagement: | |
| | can and does have a significant and positive impact on the design, delivery and monitoring of services. Through listening to people and engaging with them on changes, we can achieve better outcomes and services. | |
| | can provide additional learning and development opportunities for those involved. | |
| | Offers collaboration, preventing a sense of division within a group of people. | |
| | In planning, developing and delivering coproduction activities the following tools will be used: | |
| | The <u>Autism Friendly Communications Top tips</u> developed through coproduction to support us to work with autistic people and their parents/carers. | |
| | The Norfolk's Ethical Framework principles developed through coproduction led by Curators of Change, to create change and guide a vision that is rooted in ethical considerations. | |
| 4.2 | There would be renumeration in the form of involvement fees for those participating in some of the co production opportunities. These would be applicable to groups containing the name 'reference' | |
| 4.3 | These rates are applicable to all but the Research project reference group. These rates are: | |

Up to 1 hour: £10.00

Between 1 to 2 hours: £15.00

Over 2 hours: £20.00

In addition – with receipts, we offer out of pocket expenses for journeys to a face to face meeting and as part of a reasonable adjustment can cover other expenses (e.g. personal assistants or carers).

Payment can be made through completion of a form and paid electronically through BACS or through a voucher.

It is important to remember that it is the responsibility of anyone receiving an involvement fee to notify the Department for Work and Pensions or Inland Revenue as this may affect your tax or benefits.

Rates for the research project will be confirmed once a decision has been made on the grant being used to fund the research project.

4.4 Autism Refresh Strategy

The current All age Autism strategy runs until June 2024. There is an Opportunity to sense check what partners did that made a difference and what else they need to do and incorporate the valuable lessons from current Norfolk All-age Autism Strategy (e.g. implementation and pandemic).

To achieve the co production of the Autism refresh strategy NCC want to work with a wide range of people in different ways:

Co-production Opportunities:

Autism Strategy Reference Group (July to Dec 2023). Who: Autistic people of all ages, parents and carers.

What we will do together:

- Coproduce the 'You said, we did' communication.
- Coproduce the 'What partners have told us is important' communication.
- Coproduce an autism friendly questionnaire.
- Sense check the analysis of the questionnaire and identify strategy themes.

Wider engagement (Oct to Nov 23)

Who: Autistic people of all ages, parents, and carer, those who work with autistic people.

- Complete a questionnaire.
- Complete a workbook.

Wider engagement (Jan to Feb 24)

Who: Autistic people of all ages, parents and carer, those who work with autistic people.

 Attend a strategy theme task and finish group and or autism library sessions.

Benefits of being involved in this:

- Celebrate the power of progress understand past and present performance to meet the needs of autistic people and their families.
- Encourage flexibility and agility understand the national drivers and align these to local partners priorities and the needs of autistic people and their families.
- New ideas and opinions to motivate change –
 to create a vision of autistic people from all
 backgrounds, ethnicities, genders, sexualities
 and ages countywide who get the support
 they need to live full and happy lives.

4.5 Re-engineering adult autism diagnostic pathways

Continued high referrals, low assessment throughput and people waiting too long for an assessment means we need to do something fundamentally different.

- National and local priorities to improve diagnostic pathways and reduce waits.
- Opportunity to learn from the private market and their delivery models (self-service and hybrid).
- Support first (to prevent needs from escalating), then clinical pathway.
- Limited post support means people don't always get the support they 'need' with needs escalating.
- Valuable lessons learnt from the pandemic.

Understand and reduce the health inequalities autistic adults face. Through exploring through coproduction themes to improve:

 Autistic adults getting the right support with a better understanding of their needs.

- Reducing adult autism waiting times.
- What drives the need for a diagnosis.

Co-production Opportunities:

Autism Conversation (July to Sept 2023).

Who: Autistic people, parents/carers and those who work with autistic people.

What we will do together.

- Explore how we raise awareness of autism and promote self-recognition?
- Explore what support people need to meet their primary need of autism?
- Explore a self service and hybrid model of diagnostic assessment for autistic people?

Themes feeds into the autism strategy work:

Wider engagement (Oct to Nov 23)

Who: Autistic people, parents and carer and those who work with autistic people.

- · Complete a questionnaire.
- · Complete a workbook.

Wider engagement (Jan to Feb 24)

Who: Autistic people, parents and carer, those who work with autistic people.

Attend a diagnosis themed task and finish group

Benefits of being involved in this:

- Share your views on the support autistic people need to meet their needs first and diagnosis to follow.
- Obtain a greater understanding of adult autism diagnostic pathways and opportunities for system change.
- Inform how the current pathways can improve and develop, tackling the health and care inequalities for autistic adults.

| Agenda | Break | Action and |
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| Item 5 | | Due Date |

| 5.1 | A 10-minute break was held | |
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| Agenda Item 6 | Co-Production opportunities Part 2 | Action and Due Date |
|------------------|---|---------------------|
| 6.1 | Research Proposal | |
| | We have submitted a bid for research funding from the UEA Health and Social Care Partnership. This will enable us to carry out research to support the evaluation of the new adult autism short-term service. | |
| | Opportunity to gather robust evidence to plan how we evaluate and develop the service. | |
| | TW/KD should find out if project has been successful in obtaining funding by the end of July. If the application for funding is not successful, some of the planned activities to support the evaluation of the new service, will still be conducted. | |
| | Co-Production Opportunities: | |
| | Autism Research Reference Group (October 2023 – March 2024) | |
| | Who: autistic adults and parents/carers. | |
| | The group will meet once a month for six months, throughout the research project. | |
| | It will oversee the project, checking project plans, and helping to develop and test the questionnaire. | |
| | Complete the online questionnaire (November 2023 – January 2024) Who: autistic adults and parents/carers. | |
| | The questionnaire will ask about: | |
| | Your wellbeing and how best to measure wellbeing. | |
| | Your views about what the service can offer and how to measure whether it is successful. | |
| | Whether you would be willing to take part in an optional interview. | |
| | Interviews (January 2024) Who: autistic adults and parents/carers who have completed the questionnaire and are willing to be interviewed. | |
| | Numbers will be limited. | |
| 6.2 | If we are not successful in the bid for research funding, then we will still offer the online questionnaire and interviews and use the learning from them to plan our evaluation of the new service. | _ |

6.3 **Benefits of being involved in this:**

- May be of national interest and importance, given the current lack of autism social care research.
- Will be used to improve the short-term service and inform how it may expand and be developed in future.
- Will consider how further research can build on this project, leading to more opportunities for autism research in Norfolk.

6.4 Adult Social Care Information

Autistic people have told Adult Social Services that they would like better information before a social care assessment, to:

- Help them prepare for the assessment.
- · Reduce anxiety about what is involved.

The leaflets and website information are general for all adults with care and support needs. They are not directly relevant for many autistic people.

Adult Social Services want to make it easier for practitioners to send relevant information to autistic adults in advance of their assessment.

Co-production Opportunities:

Autism Social Care Reference Group (Sept to Dec 23).

Who: Autistic adults, ideally a mix of people who have experience of a social care assessment, and others who do not.

What we will do together.

- Review information resources currently available.
- Consider what works well and what doesn't?
- Create some information resources for social care practitioners to send to autistic adults before an assessment.

Delivered through 4 sessions, with options about how to get involved:

- group workshops online or in person, with reading beforehand.
- one-to-one email (based on individual preference).

| 6.5 | Naming the short-term service | |
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| | Adult Social Services are asking for input from Autistic people to help name the new short term support service. This can be done be answering an online survey which can be found here: https://forms.office.com/e/v0uQSdsHEH | |
| 6.6 | Anyone who is interested in participating in any of the co-production opportunities is asked to contact: | |
| | Tracey Walton: tracey.walton@norfolk.gov.uk | |
| | Karen Dures: | |
| | karen.dures@norfolk.gov.uk | |
| | Lee Gibbons: contact@norfolkautismpartnerhsip.org.uk | |
| | Please state which reference group you would like to be involved with: | |
| | Autism Strategy Reference Group. | |
| | Autism Research Reference Group. | |
| | Autism Social Care Reference Group. | |
| 6.7 | MB said that they are currently updating the Norfolk Area SEND Strategy and this would be good to link up all these opportunities so they can be reflected in that document, which will be known as: Norfolk Area Special Educational Needs and/or Disabilities (SEND) and Alternative Provision Strategy (NASAPS) | |

| Agenda Item 7 | Talking Therapies | Action and Due Date. |
|------------------|--|----------------------|
| 7.1 | The NAPB welcome Diane Smith who spoke to us about the upcoming procurement process for the Talking Therapies services (also known as Wellbeing service) | |
| 7.2 | Anxiety or depression-based conditions that can be supported by a single clinician. Uses evidence based talking therapies. Trains and supervises a workforce. Monitors outcomes | |

| | It is available for anyone over the age of 16. |
|-----|---|
| 7.3 | The service aims to support 30,000+ people a year The current contract was issued in 2008 and is due for renewal in 2024. The Talking Therapies service is consulting with a wide range of people and groups to see how the service can be improved |
| 7.4 | There are some things that can be influenced by service users: • How people find out about the service • How people access the service e.g., through telephone, online or face-to-face options • Accessibility of the service – how the service adapts to needs in different groups to enable engagement • How the service communicates with users of the service, the public and professionals • How the service connects across the 'system' |
| 7.5 | There are somethings that cannot be changed: Range of needs treated. Treatment offered |
| | (These are set out by National Institute for Health and Care Excellence) |
| | Training required. (This is set out by National Health Service England / Health Education England) |
| | Flow of data to national reporting |
| 7.6 | Talking Therapies have already spoken to a wide group of people: |
| | Community Voices |
| | Healthwatch Norfolk and Healthwatch Suffolk |
| | 'Lets Talk About Mental Health' report as a result of the Integrated Care Board public survey |
| | "We still need to talk" report from 2013 but still has useful feedback on Service User experience |
| | Norfolk and Suffolk NHS Foundation Trust staff survey feedback |
| | Mental Health in primary care feedback |
| | Feedback received by the service from service users, including complaints and compliments |
| | Current data reports |
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| 7.7 | They have launched selection of surveys for the public, key stake holders and professionals who work within the service. | |
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| 7.8 | To access the public survey please click this link: https://improvinglivesnw.org.uk/lets-talk-talking- therapy/ This survey is live until 24th July 2024 | |

| Aganda | Any Other Rusiness | Action and Duc |
|------------------|---|----------------------|
| Agenda Item 8 | Any Other Business | Action and Due Date. |
| 8.1 | LG gave an update on his involvement with the rollout of the Oliver McGowan Mandatory training in Learning Disabilities and Autism. | |
| 8.2 | A meeting between NAPB/ASD Helping Hands, Opening Doors and Joanna Yellon has been arranged to see how they can support people with a Learning Disability and Autistic people to help facilitate the face to face section of the training. | |
| 8.3 | LG also informed the NAPB that he has applied to become a trainer for the Oliver McGowan training and is waiting to hear back from NHS England | |
| 8.4 | The first Oversight Board took place on the 10/07/2023 and had 5 attendees. The five priority areas they want to explore are: • Adult Social Care Assessments • Mental Health Support • Employment Support • Diagnosis • Lived experience in Schools (specifically for Teachers) | |
| 8.5 | TK asked the Partnership Board to support the collection of case studies for the Charging Reference group. They are currently looking for case studies on the following areas: 1. Have you had a Care Act Assessment recently? 2. Have you had a Financial Assessment recently? 3. Have you recently had advice on managing debts, related to social care costs? 4. Have you given feedback recently to try and make social care better? | |
| 8.6 | LE asked about presenting at the Partnership Board as an Autistic Adult as we have had a string of professionals present. TK said that this would just be a case of emailing Lee Gibbons with a topic they would like to discuss | |

| | and then the co-chairs and put it on the agenda if relevant. | |
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| 8.7 | Action: To facilitate a presentation from LE for next Partnership Board meeting. | Lee Gibbons 19/09/2023 |
| 8.8 | LG advised that he would be sending 2024 Board meeting dates out over the next few days. | |

| Agenda Item 9 | Close of Meeting | Action and Due Date. |
|------------------|--|----------------------|
| 9.1 | The Co-chair closed the official meeting | |

| Agenda Item 9 | Post Meeting Support | Action and Due Date. |
|------------------|---|----------------------|
| 9.1 | 30 Minutes was provided at the end of the meeting as a reasonable adjustments and to provide support to those who attended the meeting. | |

Date, time and location of next meeting

Thursday 28 September 2023 11:00-13:00 (Microsoft Teams)

Upcoming Meeting Dates

Tuesday 21 November 2023

Tuesday 30 January 2024

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

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