

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

**Held on: Wednesday 25 July 2018, 10:00 – 13:00**

**Venue: Kings Centre, Queen Anne's Road, Great Yarmouth, Norfolk,  
NR31 0LE**

**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; NCC Executive Director Adult Social Services                                  |
| Clare Smith             | Co-chair of AAAPB; Autistic adult   |
| Zandrea Stewart         | NCC Assistant Director Integrated Commissioning and Transformation; vice-co-chair AAAPB |
| Rosemary Boutet         | Older autistic person   |
| Sharon Brooks           | Voluntary sector representative<br>Chief Officer, Carers' Council                       |
| Sue Bridges             | Norfolk & Suffolk Foundation Trust (NSFT)   |
| Jared Carpenter         | Autistic adult  |
| Toni Collinson          | Norfolk Constabulary  |
| Alastair Corrigan       | Business Support Officer, Adult Social Services, NCC                                    |
| Alison Furniss          | Voluntary sector representative<br>Family Voice   |
| Tracy McLean            | NHS Clinical Commissioning Group (CCG) representative – Children                        |
| Claire Miller           | Family member/carer of autistic person  |
| Jocelyn Pike            | NHS Clinical Commissioning Group (CCG) representative - Adults                          |
| Mark Rushen             | Autistic adult; vice-co-chair AAAPB   |
| Alexandra Smith         | Young autistic person   |
| Stephanie Tuvey         | Health Watch  |

| <b>Apologies Received</b> | <b>Organisation and or Role</b>                      |
|---------------------------|--|
| Joanna Corbyn             | Family member/carer of autistic person               |
| Lee Gibbons               | Voluntary sector representative<br>ASD Helping Hands |
| Hayley Griffin            | NCC Children's Services                              |
| Catherine Haig            | Asperger Service Norfolk                             |
| Lauren Lonergan           | Young autistic person                                |
| Michelle Trollope         | Norfolk Community Health & Care NHS Trust            |
| Carolyn Watts             | Public Health, NCC                                   |

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| Kim Woodrow | Family carer representative |
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| Observers         | Organisation and or Role                                 |
|-------------------|--|
| Tracey Walton     | Autism Commissioning Manager, Adult Social Services, NCC |
| Maxine Blocksidge | Senior Adviser SEND, Children's Services, NCC            |

| Name of Presenter | Organisation and or Role   |
|-------------------|--|
| Michael Bateman   | NCC Head of Education High Needs SEND Service, Children's Services |

| Agenda Item 1 | Welcome and Introduction   | Action and Due Date |
|---------------|--|---------------------|
| 1.1           | Clare Smith welcomed everyone to the meeting.  |                     |
| 1.2           | All were asked to complete the GDPR-compliant data consent form.   |                     |
| 1.3           | Everyone introduced themselves. Clare Smith welcomed Claire Miller and Rosemary Boutet as it was their first meeting. Clare Smith also welcomed Maxine Blocksidge who will replace Michael Bateman.<br><br>Zandrea Stewart introduced Tracey Walton. |                     |

| Agenda Item 2 | Minutes of previous meeting (30/04/18) and matters arising not on the agenda.  | Action and Due Date |
|---------------|--|---------------------|
| 2.1           | The following amendments to the previous minutes were agreed: <ul style="list-style-type: none"> <li>4.1.4: 'NCC's plan... to give more training to some individuals</li> <li>5.1.4: <u>Adults'</u> and Children's...</li> </ul> Alastair will update the previous minutes with these amendments.  | Alastair Corrigan   |
| 2.2           | All agreed that full names of participants will be used in the narrative of future minutes.  |                     |
|               | <b>Matters arising:</b>  |                     |
| 2.3           | Item 2.5 – The Terms of Reference, which had been circulated, state that members must attend at least three of the four annual meetings. The current proposed meeting times is creating difficulties for some autism representatives.<br><br>James Bullion suggested attendance by autism representatives could be looked at on a case-by-case basis. The meeting agreed.<br><br>The Terms of Reference will need to be amended accordingly. | Alastair Corrigan   |
| 2.4           | Item 3.2.1 – Rosemary Boutet will approach the Norfolk Older People's Partnership Board to suggest   | Rosemary Boutet     |

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|      | they nominate an additional older autistic person representative   |                   |
| 2.5  | Item 3.2.2 – Tracey McLean said CAMHS had not nominated a representative as the service was still being re-designed. She suggested she would stand down as a CCG representative and attend as the CAMHS representative instead. The meeting agreed to this.  |                   |
| 2.6  | Item 3.2.4 – the AAAPB had been told an integrated autism lead had been appointed. However, Tracey Walton has been appointed as Autism Commissioning Manager for NCC alone. She will work with the CCGs, but Clare Smith expressed concerned at the loss of full integration. James Bullion offered to discuss this further with Clare outside the meeting.  | James Bullion     |
| 2.7  | Item 3.3 elections to vacant seats on the Board. Members were advised the period for expressions of interest has been extended, to allow more autistic people to stand. The elections will be completed by our next meeting, which the new members will be invited to attend.  | Alastair Corrigan |
| 2.8  | Item 4.1.2 - The draft Joint Strategic Needs Assessment (JSNA) was circulated prior to the meeting. The document is a mapping of all age future needs. Clare Smith noted that the document contains many issues which need addressing before it can be published.  |                   |
| 2.9  | <p>Sarah Gentry (Public Health Registrar, NCC) had asked for feedback on the draft from AAAPB members.</p> <p>Expressions of interest to take part in a feedback meeting were noted from:</p> <ul style="list-style-type: none"> <li>• Rosemary Boutet</li> <li>• Maxine Blocksidge</li> <li>• Jared Carpenter</li> <li>• Sarah Gentry</li> <li>• Clare Smith</li> <li>• Tracey Walton</li> </ul> <p>Alastair Corrigan will arrange the meeting.</p> | Alastair Corrigan |
| 2.10 | Alexandra Smith expressed her concern at the lack of engagement on this and in a wider sense with the autism community to date. James Bullion said that the JSNA will not be signed off without engagement from the autism community.  |                   |
| 2.11 | A final draft of the JSNA will be discussed at the AAAPB meeting in October. The Board agreed to call it an 'interim' JSNA until the strategy is complete.   | Carolyn Watts     |

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| 2.12 | 4.1.3 – covered by Data collection update (see 3.3, below)  |                             |
| 2.13 | 4.1.4 – covered by Workforce Development and Training update (see 3.1, below)   |                             |
| 2.14 | 4.1.5 – Children’s autism diagnostic pathway: Tracy McLean confirmed that the CCGs are now aware how difficult it is to get diagnoses and assessments.  |                             |
| 2.15 | 4.1.5 – Clare Smith had asked for a copy of the children autism diagnostic pathway to be shared with April’s AAAPB meeting, though she accepted her meaning might have been misinterpreted.<br><br>Although three documents were circulated, none of them were a diagnostic pathway. Tracy McLean disagreed.<br><br>Clare Smith repeated her request for the full children’s autism diagnostic pathway to be shared with the Board. | Tracy McLean                |
| 2.16 | 4.1.6 – adult autism diagnostic pathway - covered by Diagnostic Pathways update (see 3.5, below)  |                             |
| 2.17 | 6.1 – Clare Smith updated members: Patricia Hewitt (Chair of Norfolk’s Sustainability and Transformation Programme (STP)) has agreed to attend our next Board meeting to discuss the STP’s work and how it will impact on autism services.  |                             |
| 2.18 | The previous minutes were approved by all except for Clare Smith, subject to the amendments agreed in 2.1.<br><br>The co-chairs agreed to discuss further to reach agreement and present a final draft to the next AAAPB for ratification.  | James Bullion & Clare Smith |
| 2.19 | The length of time taken to go through the minutes was acknowledged. The Board agreed that minutes will need to be agreed by the Co-Chairs in advance of future meetings.   | James Bullion & Clare Smith |

| <b>Agenda Item 3</b> | <b>Updates from Working Groups</b>   | <b>Action and Due Date</b> |
|----------------------|--|----------------------------|
| 3.1                  | <b>Workforce Development and Training</b><br>The working group’s report was noted and approved.  |                            |
| 3.2                  | <b>Engagement</b><br>Lee Gibbons was unable to attend the meeting. The group’s report was noted and approved.  |                            |
| 3.3                  | <b>Data collection</b><br>Mark Rushen is the new working group lead. Zandrea Stewart submitted a report outlining the data that organisations currently collect. | Alastair Corrigan          |

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|       | <p>Clare Smith and Alexandra Smith said they had difficulty in understanding the dashboard that was circulated. Zandrea Stewart agreed to arrange for the report to be updated to make it easier to understand and re-circulated for the next meeting.</p> <p>Zandrea Stewart confirmed that autistic people aren't recorded by Norfolk County Council as having autism unless they have a learning disability as well. It is hoped this will change in the future.</p> <p>Ms Stewart's report was noted and approved.</p> |               |
| 3.4   | A glossary of terms will be developed, to explain the meaning of commonly used terms and acronyms.   | Tracey Walton |
| 3.5.1 | <p><b>Diagnostic Pathways</b></p> <p>Adults': Clare Smith had been sent information about Asperger Service Norfolk (ASN) she'd first asked for in March, but noted it was supplied only the day before the meeting, leaving her no time to properly process it. It was not shared with other members.</p>  |               |
| 3.5.2 | She advised the Board the information supplied was out of date, for example, not mentioning the vacancies ASN has operated with for several months. She sought clarification on a number of other elements in the information.   | Jocelyn Pike  |
| 3.5.3 | Jocelyn Pike accepted that the adults' diagnostic pathway needs to be revised to comply with NICE guidance and for transparency.   |               |
| 3.5.4 | The WG will continue to press for CCGs to share their plans so the autism community can influence them.  | Jocelyn Pike  |
| 3.5.5 | Rosemary Boutet said that people with autism have experienced problems with the pathway for many years.  |               |
| 3.5.6 | Children's: Tracy McLean said she had responded to concerns raised by the autism community. Clare Smith agreed but added that none of the three documents sent to her in response to her request for a copy of the diagnostic or care pathway were the pathway.  |               |
| 3.5.7 | Clare Smith advised the Board she had found a version on the internet and asked for confirmation if it was the current pathway. If not, she repeated her request.  | Tracy McLean  |
| 3.5.8 | The NHS was working to bring the waiting time for first assessment appointments down to a year or less. Tracy McLean will send a summary version of the paper recently discussed by Norfolk's Health Overview and Scrutiny Committee (HOSC) to the Board.  | Tracy McLean  |

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| 3.5.9 | Clare Smith felt there were inaccuracies in the diagnosis WG report. These will be addressed and amended at the next working group meeting.<br><br>The WG's report was noted and approved. | Zandrea Stewart |
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| <b>Agenda Item 4</b> | <b>Co-Production</b>  | <b>Action and Due Date</b> |
|----------------------|---|----------------------------|
| 4.1                  | Clare Smith addressed the Board about the sense of the lack of true co-production felt by many members of the wider autism community, due to the statutory authorities continuing to try to manage the process without fully involving autism members.  |                            |
| 4.2                  | She noted that she has had to fight for concessions and has at times felt she is being treated as a token autistic co-chair.<br><br>One example she gave was the first report about the AAAPB's work submitted to the July Health & Wellbeing Board. No autism representative was asked to contribute to it, but it gave the impression we had co-produced it. It presented a much rosier picture than is accurate. |                            |
| 4.3                  | She also noted how hard Zandrea Stewart has been working to achieve our joint agenda and she made several suggestions she hoped members would adopt to tackle the issue, including enabling autism members to become more knowledgeable about statutory authority processes.  |                            |
| 4.4                  | Mark Rushen said he felt there already is some co-production and that is important to draw a line under the past.   |                            |
| 4.5                  | Zandrea Stewart developed one of Clare Smith's suggestions, and suggested workshop training for all Board members in co-production and partnership working, with an independent facilitator. All agreed with the suggestion.  | Zandrea Stewart            |

| <b>Agenda Item 5</b> | <b>Update from Autism Partnership Group (APG) meeting (9 July 2018)</b>   | <b>Action and Due Date</b> |
|----------------------|---|----------------------------|
| 5.1                  | Following some critical feedback from members of the public, future APG meetings will be held in different locations across Norfolk and at parent-friendly times. |                            |
| 5.2                  | Clare Smith informed the Board that she had followed up on feedback in the AAAPG meeting and had invited Sara Tough (NCC Executive Director of Children's         |                            |

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|     | Services) to attend this meeting to discuss their practice/policy on EHCPs. Ms Tough has declined.<br>Michael Bateman suggested this may have been because Ms Tough had recently met with ASD Helping Hands and so she may have felt she'd 'done' autism. |               |
| 5.3 | James Bullion said he would speak to Sara Tough to clarify. He suggested it might be important to invite a senior member of Children's Services to attend future meetings.  | James Bullion |

| <b>Agenda Item 6</b> | <b>Membership Update</b>   | <b>Action and Due Date</b> |
|----------------------|--|----------------------------|
| 6.1                  | Nikki Elliott had resigned before this meeting. Clare Smith advised that Alexandra Smith was also resigning with immediate effect (Ms Smith had left the meeting during the break).  |                            |
| 6.2                  | This meant that there were vacancies for the following: <ul style="list-style-type: none"> <li>• One young autistic person (aged 14-24)</li> <li>• One autistic adult (aged 25-54)</li> <li>• One older autistic person (aged 55 or over)</li> </ul> |                            |
| 6.3                  | The Board agreed to use a formal voting process. The new representatives are expected to be in place for the next Board meeting.   | Alastair Corrigan          |

| <b>Agenda Item 7</b> | <b>Resources for Autism</b>  | <b>Action and Due Date</b> |
|----------------------|--|----------------------------|
| 7.1                  | James Bullion said that future funding will need to be defined by the actual level of need, gaps in the system and the models by which people will need to be supported. |                            |
| 7.2                  | Sue Bridges said there would be less impact on mental health services with resources for autism in place.  |                            |

| <b>Agenda Item 8</b> | <b>SEND: Education, Health and Care Plan (EHCP)</b>  | <b>Action and Due Date</b> |
|----------------------|--|----------------------------|
| 8.1                  | Michael Bateman presented a PowerPoint on EHCPs.   |                            |
| 8.2                  | He said his department is currently under-staffed to deal with the increased volume of referrals and high number of annual reviews required. |                            |
| 8.3                  | Mark Rushen expressed concern about children and young people in the County with a high level of need who have been refused assessments.     |                            |



| <b>Agenda Item 9</b> | <b>AAAPB Communications plan</b>  | <b>Action and Due Date</b> |
|----------------------|---|----------------------------|
| 9.1                  | The Autism page on NCC's website has been updated with proposed future AAAPB and APG meeting dates. NHS organisations have been asked to link to it but it was noted that no autism member has had any input to it.   |                            |
| 9.2                  | All agreed to adopt the logo developed and gifted by Clare Smith.   |                            |
| 9.3                  | Below is a link to a recent paper article regarding the work of the AAAPB arranged by Clare Smith:<br><a href="http://www.edp24.co.uk/news/health/how-mother-and-daughter-diagnosed-with-autism-on-the-same-day-have-bounced-back-to-help-others-1-5524869">http://www.edp24.co.uk/news/health/how-mother-and-daughter-diagnosed-with-autism-on-the-same-day-have-bounced-back-to-help-others-1-5524869</a> |                            |
| 9.4                  | Oliver Cruickshank (South Norfolk CCG) will start attending the Engagement Working Group to start developing a communications plan.   |                            |

| <b>Agenda Item 10</b> | <b>Development of Norfolk's All Age Autism Strategy</b>   | <b>Action and Due Date</b> |
|-----------------------|---|----------------------------|
| 10.1                  | A draft Norfolk Autism Strategy was circulated prior to the meeting.  |                            |
| 10.2                  | The Board agreed to set up a task-and-finish group to develop the draft Strategy, and to present the final draft at our October meeting.<br><br>Zandrea Stewart, Tracey Walton and Clare Smith volunteered to join the group. Mark Rushen offered to review the document but said he could not commit to the time needed to attend the t&f group. | Tracey Walton              |
| 10.3                  | Sue Bridges said that the logos used in the Strategy document should refer to the organisations involved in its development. The meeting agreed.  |                            |
| 10.4                  | Zandrea said she hoped all members would give feedback on the draft strategy following the meeting.   |                            |

| <b>Agenda Item 11</b> | <b>Welcome and Introduction</b>  | <b>Action and Due Date</b> |
|-----------------------|--|----------------------------|
| 11.1                  | The Autism Self-Assessment Framework (SAF) has not yet been released. This item was not discussed. |                            |

| <b>Agenda Item 12</b> | <b>Welcome and Introduction</b>   | <b>Action and Due Date</b> |
|-----------------------|---|----------------------------|
| 12.1                  | Autistic people and family members/carers who attend these meetings were told they can claim an involvement fee of up to £20 per meeting, plus travel |                            |



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|      | expenses. Claim forms have been circulated electronically.       |  |
| 12.2 | An overview of the process was circulated prior to this meeting. |  |

| <b>Agenda Item 13</b> | <b>Possible agenda items for next meeting</b>                                       | <b>Action and Due Date</b> |
|-----------------------|---|----------------------------|
| 13.1                  | James Bullion suggested an item regarding Criminal Justice and Prisons. All agreed. |                            |

| <b>Agenda Item 14</b> | <b>Any Other Business</b>  | <b>Action and Due Date</b> |
|-----------------------|--|----------------------------|
| 14.1                  | A one-day autism awareness training course is proposed for all members of the AAAPB shortly before the next meeting on October. Members will be asked about their availability.          | Alastair Corrigan          |
| 14.2                  | Zandrea Stewart said she had asked Tracey Walton to compile summary of the work of current working groups and possible future WGs.   | Tracey Walton              |
| 14.3                  | A list of proposed meeting dates for the AAAPB and APG had been circulated. Board members were asked to submit feedback following the meeting so a calendar of meetings can be arranged. | Alastair Corrigan          |

| <b>Date, time and location of next meeting</b>  |
|---|
| <b>To be confirmed.</b><br>Provisionally arranged for Thursday 4 October, 12.30-3.30pm at County Hall, Norwich. |