

Report title:	Autism Strategic Update
Date of meeting:	10 July 2019
Sponsor (H&WB member):	James Bullion, Executive Director Adult Social Services
<p>Reason for the Report This report provides an update on the Norfolk All-Age Autism Partnership Board (NAPB), its progress to put in place a Norfolk autism strategy and to support the implementation of the Autism Act (2009) National Autism Statutory Guidance (2016) and Strategy 'Think Autism'. It provides information on the activity underway to support the statutory bodies' responsibilities in undertaking their duties under the Autism Act 2009, Statutory Guidance 'Think Autism' 2014, Care Act 2014 and the Equality Act 2010.</p> <p>Report summary This report provides an update on the All-Age Autism Partnership Board and the workstreams in place to support the implementation of a coproduced local All-Age Autism Strategy 'My Autism, Our Lives, Our Norfolk'.</p> <p>Recommendations: The HWB is asked to support and commend the work undertaken by autistic people to coproduce the local All-Age Autism Strategy 'My Autism, Our Lives, Our Norfolk' and establish effective working groups. To enable the implementation of the strategy, the recommendations are that:</p> <ul style="list-style-type: none"> a) The autism strategy 'My Autism, Our Lives, Our Norfolk' is approved. b) All Health and Wellbeing Board members embed the strategy within their own organisations, for example by promoting participation in autism training. c) All Health and Wellbeing Board members complete the Autism e-learning training themselves and campaign to increase its use across the partnership. 	

1. Background

- 1.1 The introduction of the Adult Autism Act 2009 and its associated guidance, required local area partnerships to ensure the delivery of the Autism Act 2009, the Autism Strategy and the Autism Statutory Guidance. To do this, a leadership role was given to local authorities and health and well-being boards.
- 1.2 To support this undertaking, local areas have been encouraged to facilitate the creation of a local Autism Partnership Board (or an appropriate alternative). In addition, local areas are to undertake the completion of the National Autism Self-assessment, which enables the local partnership to demonstrate progress and identify priorities needed to form a local autism plan.
- 1.3 The National Autism Self-Assessment provides the Department of Health with the local area evidence required to undertake the assurance function placed upon them by the Autism Act 2009. The Self-Assessment Framework (SAF) consists of 129 questions.

The local self-assessment was coproduced and submitted in December 2018. The outcomes from the SAF are incorporated in the Autism Strategy 'My Autism, Our Lives, Our Norfolk'.

- 1.4 The current prevalence of people with autism spectrum disorder (ASD) among the general population is approximately 1%. The following data comes from estimated figures from draft JSNA 2018.
- a) There were an estimated 5080 adults (aged 16-64) with ASD in Norfolk in 2017, projected to rise slightly up to 5211 by 2035 (PANSI 2016).
 - b) There were an estimated 2039 older adults (aged 65+) with ASD in Norfolk in 2017, projected to rise considerably to 2826 by 2035 (POPPI 2016).
 - c) There were an estimated 2491 children and young people (aged 0-19) with ASD in Norfolk in 2016 (ONS 2017; Baird et al. 2006).
 - d) As of April 2018, Norfolk County Council was supporting 503 autistic adults. 123 of these were recorded as having Asperger's Syndrome and 91 as having autism. Separately, 57 had a mental illness listed as their primary diagnosis alongside their record as being autistic.
 - e) In 2016 there were an estimated 2491 children and young people with autism in Norfolk. In 2017, 7.15% of the SEN cohort was identified as having ASD.
- 1.5 Following a focused period of engagement with the autism community and their families, the co-produced Norfolk All-Age Autism Partnership Board had its first meeting in April 2018. Key priorities for the Board were identified as: workforce development and training; engagement with people; diagnostic pathways; and data collection.
- In October 2018, following continuous engagement with autistic residents and their families in Norfolk, education was agreed as an additional priority. Working groups were set up to achieve key objectives. Other priority work identified included housing, criminal justice, health and wellbeing.
- 1.6 The Health and Wellbeing Board is named within the national Autism Strategy as the local strategic partnership to oversee progress locally. The Health and Wellbeing Board was provided with an update on the work of the NAPB on 14 January 2019, with the Board:
- a) acknowledging the development of the Norfolk All Age Partnership Board
 - b) acknowledging and supporting the development of working groups to undertake priority work
 - c) agreeing to receive the local All-Age Autism Strategy that will be informed by the completion of the National Autism Self-Assessment (2018)
 - d) supporting the undertaking of a community engagement exercise that will seek to identify life experience of people with autism and their families living in Norfolk.
- 1.7 The autism statutory guidance reminds local authorities of the requirements of the Children and Families Act and the Special Education Needs (SEND) reforms by to include the needs of young people with autism in their Education, Health and Care Plans (EHCP) and Preparing Young People for Adulthood transition planning.
- 1.8 Presentations to both the Children's Services Committee and the Clinical Commissioning Group's (CCG) Joint Strategic Committee will ensure full engagement with, and integrated focus of, the strategy.
- 1.9 As part of the wider responsibilities of the Council beyond providing health and social care, Officers and the Board will continue to work on promoting a wider understanding of autism and encourage people's equal participation in their communities.

2. Norfolk Autism Strategy

- 2.1 Over the past year significant steps have been taken to continue realising the ambition of a comprehensive, inclusive autism strategy. Increasing engagement with the autism

community, including with people who are not currently involved with social care services and do not have a Learning Disability, has been a key part of that process. We have proactively engaged in challenging conversations with a wide range of people, including those who have been dissatisfied with access to services and the progress that has been made across the system, to achieve a robust outcome.

2.2 This increase in engagement can be evidenced through an increase in the number of new members belonging to the autistic community welcomed onto the Norfolk All-Age Autism Partnership Board (NAPB), as well as an increase in the number of people interested in the work of the Board in general.

2.3 'My Autism, Our Lives, Our Norfolk'

2.3.1 Co-production of the draft autism strategy was achieved using a variety of methods throughout 2018 and 2019. A series of community engagement 'conversations' were arranged at quarterly intervals throughout 2018 to gather data in preparation for creating the Strategy. An additional strategy focused meeting was arranged in late November 2018, with a further follow up conversation held in February 2019. Throughout the entire period, group conversations took place with autistic people, parents, carers, the third sector and service providers as well as 1:1 conversations for those individuals who expressed their dislike attending groups.

The draft autism strategy was shared with the 59 registered members of the Norfolk Autism Partnership Group and the NAPB board members on 28 March. The draft strategy was also distributed at the autism awareness event held at the Norwich Forum on 5 April for World Autism Week. We received 15 responses, the contents of which have all been reflected within the strategy.

2.3.2 To give the strategy ownership, meaning and purpose, 'My Autism, Our Lives, Our Norfolk' was named by autistic people. It sets out a vision for all individuals and families affected by autism to have the same opportunities to live fulfilling and rewarding lives as anyone else, across their entire lifetimes: whether they are a child, a young person, an adult or an older person. Norfolk's All Age Autism Strategy, *My Autism, Our lives, Our Norfolk* can be found in Appendix A, with an easy read version available [here](#).

2.3.3 'My Autism, Our Lives, Our Norfolk' aims to make Norfolk an Autism Friendly County. It seeks to raise public and professional awareness of autism to ensure that people with the condition are accepted, understood and treated fairly within their communities.

2.3.4 'My Autism, Our Lives, Our Norfolk' includes outcomes and recommendations from:

- a) The National Autism Self-Assessment, completed on 14 December 2018.
- b) The Healthwatch Norfolk report 'Access to health and social care services for Norfolk families with Autism'.
- c) All-Age Autism Joint Strategic Needs Assessment.

2.4 Implementation of the Strategy 'My Autism, Our Lives, Our Norfolk'

2.4.1 'My Autism, Our Lives, Our Norfolk' is a five-year strategy with nine priorities. These nine priorities will be reviewed annually each September by the NAPB. The review will take into consideration national and local policy and guidance to inform a plan for action with measurable objectives. This Action Plan will be considered by the Council and the local NHS plan services.

The National Autism Programme will undertake a refresh of the National strategy in 2019. Department of Health and Social Care (DHSC) have indicated that this will be an all-age strategy which is positive and aligned with 'My Autism, Our Lives, Our Norfolk'.

2.4.2 Through our continued consultations, people affected by autism in Norfolk tell us the continued need to prioritise the five fundamental areas.



2.4.3 Working Groups:

The workstreams meet regularly to address the priorities.

The Health and Wellbeing Board is asked to participate in the training and encourage staff to complete the autism e-learning programme and where appropriate face to face autism training. In addition, encourage staff to participate in autism awareness raising and furthermore prompt the accurate recording to support the creation of an autism dashboard.

Rethink Partners were commissioned by Norfolk County Council and the CCGs to conduct research on neurodevelopmental disorders (NDD) that includes autism pathways. The Rethink Partners report is produced with system leaders working on a response and action plan.

3. Engagement, Coproduction and Progress

3.1 To genuinely co-produce a meaningful strategy and, even more importantly, to increase and improve communication with and between the autistic community and public bodies, a number of strategies and dialogues have been initiated.

3.2 Norfolk All-Age Autism Partnership Board (NAPB) – the Board itself.

3.2.1 NAPB membership includes nine autistic members with older people, working age adults, young people and parents/carers representatives along with the public sector, voluntary and third sector representatives. Efforts are being made to consider the size and makeup of the board to ensure coproduction is effective and efficient.

3.2.2 The Board commissioned an independent review of the whole NAPB. The final report made a number of positive recommendations. Implementation plans have been put in place through the 'NAPB Communication and Engagement Plan'. The NAPB continues to improve its relationships between autistic communities and the Council. There is an intense desire for board members to work constructively and in partnership.

3.2.3 A review meeting of the Board took place in September 2018 and identified a programme plan of activities to be achieved. These plans continue to be reviewed and updated by the autism commissioner and working group leads. The next review is due late September 2019.

3.2.4 The Board's terms of reference and venue standards document is available on the Council's website at the following link: <https://www.norfolk.gov.uk/what-we-do-and-how-we-work/policy-performance-and-partnerships/partnerships/all-age-norfolk-autism-partnership-board> (accessed 06 June 2019)

3.3 The National Autistic Society was approached and agreed to run a workshop for Board members on the 4th September 2019 to explore what good coproduction means, looks and 'feels' like. The outcome of the workshop is for members to gain a shared understanding of co-production, the roles and contributions of all members of the

partnership and agree on how to best size and scope the Board to provide meaningful engagement and outcomes.

3.4 **Autism Training**

3.4.1 Autism Training for Board members was delivered by Norfolk and Suffolk Foundation Trust on 5 December 2018. Thirteen members of the Board attended.

3.4.2 Autism training will be available to all existing and new NAPB members as part of the commissioned service 'Ambitious about Autism'.

3.5 **Joint Strategic Autism Needs Assessment**

3.5.1 NAPB members worked with Public Health to deliver a joint strategic autism needs assessment. Following two engagement opportunities to consider if the recommendations from this report are correct, the recommendations were used to draft the autism strategy 'My Autism, Our Lives, Our Norfolk'. The NAPB approved Joint Strategic autism needs assessment on the 22nd May 2019.

3.5.2 The Joint Strategic Autism Needs Assessment is available on the Council's website at the following link: <https://www.norfolk.gov.uk/what-we-do-and-how-we-work/policy-performance-and-partnerships/partnerships/all-age-norfolk-autism-partnership-board> (accessed 06 June 2019)

4. **Financial Implications**

4.1 Funding will be required for the continued activity and support of the NAPB and coproduction workshops. This has been incorporated into the overarching service budget.

4.2 Workforce development training for council staff and the wider partnership is required. Council training is being rolled out from April 2019, roll out to the wider system will have financial implications for partner organisations.

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