

Adult Social Care Committee

Item No

Report title:	Autism Strategic Update
Date of meeting:	14 January 2019
Responsible Chief Officer:	James Bullion, Executive Director Adult Social Services

Executive summary

This report provides an update on progress to support the implementation of the Autism Act (2009) National Autism Statutory Guidance (2016) and Strategy 'Think Autism'.

It provides information on 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.

The paper details the establishment of an All Age Autism Partnership Board and the wider engagement of people with autism to inform an All Age Autism Partnership Strategy for Norfolk.

Recommendations:

Adult Social Care Committee is asked to:

- a) Acknowledge the work undertaken in the continued development of Norfolk All-Age Autism Partnership Board, Norfolk All-Age Autism Group and the working groups in place to undertake priority work identified**
- b) To consider the contribution from services across Norfolk County Council (the Council) to the strategy**
- c) Agree to receive the local all-age autism strategy that will be informed by the completion of the National Autism Self-Assessment (completed 14 December 2018) with a co-produced all age strategy available March 2018**

1. Purpose of the report

- 1.1 This report is to provide an update on the continued development of the All-Age Autism Partnership Board and the workstreams in place to support the development of a local All-Age Autism Strategy.

2. Background

- 2.1 The introduction of the Adult Autism Act 2009, and associated guidance, requires local area partnerships (with a leadership role for local authorities and health and well-being boards) to assure itself of the delivery of the Autism Act 2009, the Autism Strategy and the Autism Statutory Guidance.
- 2.2 To support this undertaking, local areas have been encouraged to facilitate a local Autism Partnership Board (or appropriate alternative) and undertake the completion of a National Autism Self-assessment that enables the local partnership to demonstrate progress and identify priorities to form a local autism plan.

- 2.3 The National 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.
- 2.4 The current prevalence of people with autism in the population is approximately 1%.
- a) There were an estimated 5080 adults (aged 16-64) with Autism Spectrum Disorder (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) There are approximately 500 people known to adult social care system identified as having autism with a learning disability
 - e) In 2016 there were an estimated 2491 children and young people with Autism in Norfolk in 2016. In 2017, 7.15% of the Special Educational Needs (SEN) cohort identified with ASD was a pupil number of 1329. The figures for pupils in Norfolk special schools is 22.7% (26.4% nationally) and this is within a cohort of approximately 295 pupils
- (Estimated figures from draft JSNA 2018)*
- 2.5 A focused period of engagement with the autism community and their families over the last five months has resulted in significant progress against the Autism agenda. This work has resulted in the co-produced development of the All Age Autism Partnership Board's first meeting, which took place, in April 2018. Key work priorities for the Board have been identified as: workforce development and training, engagement with people, diagnostic pathways, data collection and education. Other priority work identified includes housing, criminal justice, health and wellbeing.
- 2.6 These priorities have been identified using the statutory organisations responsibilities and an inclusive approach that supports the continuous engagement of autistic residents and their families across Norfolk. There is a growing membership of the Autism network and expressions of interest to join the All Age Autism Partnership board.
- 2.7 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 17 July 2018, 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 Norfolk 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
- 2.8 The autism statutory guidance reminds local authorities of the requirements of the Children and Families Act and the Special Education Needs reforms by including young people's needs associated with their autism in their Educational Health and Care plans and Preparing Young People for Adulthood (transition planning).

- 2.9 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.
- 2.10 Officers and the Board will continue to work to promote a wider perspective of autism and people’s equal participation in their communities as part of the wider responsibilities of the Council beyond health and social care.

3. Norfolk Autism Strategy

3.1 Over the past six months; significant steps have been taken to continue to realise the ambition of an inclusive and comprehensive autism strategy. Increasing the engagement with the autism community, including people who are not currently engaged in social care services and do not have a Learning Disability, have been a key part of that process. We have proactively engaged in challenging conversations with 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.

3.2 This increase in engagement is evidenced through a number of new members of the autistic community welcomed onto the Norfolk All-Age Autism Partnership Board (NAPB).

3.3 A Five Year Strategy

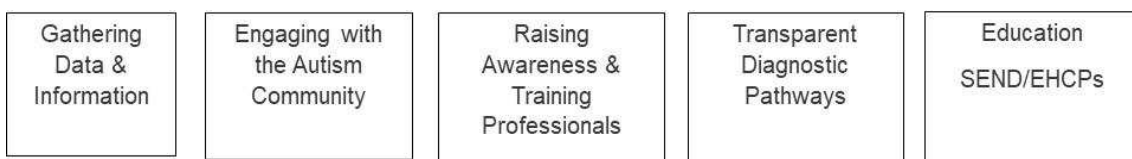
3.3.1 A series of community engagement ‘conversations’ have taken place which resulted in the co-production of the draft autism strategy. The ambition is to progress and finalise the draft strategy through further co-production and the development of an action plan. Progress will be driven by and through the NAPB.

3.3.2 The strategy will set out the vision for all individuals and families affected by autism across their lifetime, to ensure all have the same opportunities to live fulfilling and rewarding lives, whether they are a child, a young person, an adult or an older person.

3.3.3 Norfolk aims to be an Autism Friendly County and to raise public and professional awareness of autism to ensure that people are accepted, understood and treated fairly within their communities.

- 3.3.4 The Autism Strategy will include the outcomes and recommendations from:
- a) The undertaking of the National Autism Self-Assessment that was submitted on 14 December
 - b) The Healthwatch Norfolk autism report
 - c) All Age Autism Joint Strategic Needs Assessment

3.3.5 Our consultations with people affected by autism in Norfolk tell us that there are five fundamental areas we need to work on first. These are our building blocks for action, which are underpinned by our eight strategic objectives.



8 Strategic Objectives

- 3.3.6 We will translate our building blocks into an Autism Action Plan which will have measurable objectives. This Action Plan will be considered by the Council and the local NHS plan services.
- 3.3.7 As a first step we have set up five priority Working Groups. They are:
- a) **Data Gathering**
 - To improve recording of autism across local authority systems
 - To provide information to support requests for new and improved services
 - To develop a single data-base of Autism statistics
 - b) **Engaging with the Autism Community**
 - To ensure the voices of people affected by autism are heard
 - To enable the autism community to contribute to the development of services including through an Autism Communication and Engagement Plan
 - c) **Local Authority Workforce Development and Training**
 - To provide bespoke autism awareness training to all local authority and NHS staff in Norfolk
 - To provide in-person training to 'key' local authority and NHS staff in Norfolk
 - By training staff, to ensure they make reasonable adjustments to remove or reduce barriers for autistic people who need to access services
 - d) **Diagnostic Pathways**
 - To develop county-wide autism-specific diagnostic pathways for adults, children and young people in transition to adulthood which are transparent and easily understood by all
 - To ensure these pathways include effective pre- and post-diagnostic support for individuals, families and carers
 - e) **Education**
 - To support the development of SEND and education health and care plans (EHCP) to meet the needs of autistic children across Norfolk
- 3.3.8 We will bring on-stream other working groups, including – but not limited to - education, housing, employment, advocacy and support for older autistic people. This is so that by 2023 we will have achieved our overall vision of timely access to health, care and wellbeing services, and specific support for autistic people using public transport and within the education, employment, housing and criminal justice systems, among others.
- 3.3.9 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 Norfolk's all age strategy. Norfolk's strategy will be public facing and flexible with the ability to evolve considering the forthcoming refresh.

4. Engagement, Co-production and Progress

- 4.1 To genuinely co-produce a meaningful strategy and, importantly, increase and improve communication and dialogue with, and between, the autistic community and public bodies, a number of strategies and dialogues have been initiated.
- 4.2 **Norfolk All-Age Autism Partnership Board (NAPB) (the Board)**

- 4.2.1 NAPB membership includes ten autistic members with older people, working age adults young people and parents/carers representatives along with the public sector, voluntary and third sector representatives. Links have been made with the criminal justice board and the older peoples board to ensure good communication and involvement of the NAPB work.
- 4.2.2 The Board acknowledge that there has been some miscommunication and subsequent poor relationships between autistic communities and the Council however, the Board now believe that there was the opportunity and will to work constructively in partnership.
- 4.2.3 A review meeting of the Board took place in September 2018 and identified a programme plan of activities to be achieved. This plan continues to be reviewed and updated by the autism commissioner and working group leads.
- 4.2.4 Reviewed documentation of the board including terms of reference and code of conduct will be made available on the Council's website at <https://www.norfolk.gov.uk/what-we-do-and-how-we-work/policy-performance-and-partnerships/partnerships/all-age-norfolk-autism-partnership-board> as will a Venue Standards document which will be shared with venues across Norfolk.
- 4.2.5 A separate communication plan is also being developed which includes an Autism Standard for communication, it takes into account good practice from the National Autistic Society and will include access through a single point for communication and query for the autism community via the email address autism@norfolk.gov.uk and will provide consistent clear and transparent communication for the NAPB members.
- 4.3 **Co-production Session**
- 4.3.1 The National Autistic Society have been approached to run a workshop for Board members. The outcome of the workshop is to have a shared understanding of co-production, the roles and contributions of all the members of the partnership and agreement on how to best size and scope the Board to provide meaningful engagement and outcomes.
- 4.4 **Autism Training**
- 4.4.1 Autism Training for Board members was delivered by Norfolk and Suffolk Foundation Trust on 5 December 2018, 13 members of the Board attended. Conversations are taking place with Norfolk & Suffolk Foundation Trust to offer another date in early spring 2019 for those members who couldn't make this event.
- 4.4.2 Autism training will also be delivered to the Council's staff and a national expert on autism was engaged in 2018 to inform and improve the Council's approach to commissioning and delivery of services.
- 4.5 **Community Engagement Events**
- 4.5.1 Several community engagement events have taken place. A consistent theme from these forums were concerns regarding SEND, education health and care plans (EHCPs). The October 2018 NAPB agreed to form an Education SEND/EHCP working group to work through and propose solutions to the issues raised.
- 4.5.2 Further community engagement conversations are planned in February, May, August & October 2019 and February 2020.

4.6 **Joint Strategic Autism Needs Assessment**

4.6.1 NAPB members have worked with Public Health to deliver a joint strategic autism needs assessment. A second community conversation will take place in January 2019 to consider if the recommendations from this report are right; these recommendations will feed into the draft strategy.

4.7 **National Autism Self-Assessment (SAF)**

4.7.1 The National Autism Self-Assessment is how the Secretary of State evaluates how successfully local authorities have implemented the Autism Act.

4.7.2 The SAF consists of 129 questions and the outcomes from the SAF will be incorporated into the Autism Strategy. The SAF was submitted in December 2018.

4.8 **Health Watch Norfolk**

4.8.1 A report was issued in October by Healthwatch that focused on the accessibility of parents' access to a diagnosis for children and appropriate support. It identified the need for better communication with the families, particularly in helping them to understand the assessment process as well as highlighting the need for greater autism awareness across all health and care services.

4.8.2 Further suggestions include improvements to current patient waiting areas, greater family involvement in the redesign of future facilities and better wraparound support for the whole family.

4.8.3 The NAPB welcomes Healthwatch Norfolk's recommendation with all the report's findings acknowledged and to be included in the work programme of the NAPB led by Norfolk County Council and will also inform the strategy going forward.

4.9 **NHS forward Plan**

4.9.1 NHS England has identified the health needs of autistic people in addition to Learning Disabilities in the Five Year Forward View for Mental Health (2016). This is a vital step in supporting the developments that will enable autistic people to access mainstream services and promote their health and wellbeing outcomes. The NAPB looks forward to working with its health partners on making real improvements to the support autistic people receive for their physical and mental health wellbeing. Working together to be able to offer all autistic people to live, longer, happier and healthier lives.

4.9.2 The NAPB meetings held in July and October 2018 reviewed the current activity in the delivery of the National Autism Statutory Guidance and the National Autism Strategy and confirmed that the review refresh of the diagnosis and support pathways for children and adults is a priority, in addition to the development of a fifth Working Group focusing on Education.

4.10 **Communication**

4.10.1 The first of three engagement exercises is complete. The adults with autism questionnaire will help inform the priorities of the strategy including accessing a diagnosis and pre and post diagnostic support, as well as accessing and retaining employment opportunities, housing and their local community resources. The

engagement exercise will be adapted to enable as many people as possible to participate.

- 4.10.2 The exercise includes a survey, paper versions, discussions within existing peer support groups and services and schools for example.
- 4.10.3 In addition, autism community partnership groups take place four times per year and seek to widen the voices contributing to the agenda, enabling people to share their experiences on an ongoing basis and identify opportunities for people with autism to proactively support and participate.
- 4.10.4 A communication and engagement plan has been co-produced that supports the communication of the strategy and work underway. In addition to the opportunity to express an interest to participate in supporting Norfolk to be an Autism Friendly County.
- 4.10.5 As part of this plan the web page is currently being reviewed on the Norfolk County Council website and an Autism Newsletter was distributed in October 2018.
- 4.10.6 The website is updated, and a newsletter produced after each NAPB meeting, with development of news updates, with the ambition of an Autism Friendly Norfolk. The webpage and newsletters aim to:
 - a) Share where in Norfolk, a range of reasonable adjustments are considered and in place to support the needs of autistic people and their families/carers
 - b) Share involvement opportunities
 - c) Share good news stories and case studies

4.11 **Data**

- 4.11.1 The data group has been focused on the SAF, but with a future intention to hold a virtual dataset that will better inform the completion of the National Autism Self-Assessment and the planning and delivery of services in the future to be accessible and applicable for people with autism.
- 4.11.2 To improve the consistent collation of data for Norfolk guidance on how to correctly and consistently record autism has been provided with evidence of improved recording through the SAF reporting from 2016 to 2018.

4.12 **Diagnostic and Support pathways**

- 4.12.1 It is recognised that the current diagnostic pathways for both children and adults have had challenges with regards to capacity and waiting times for assessment. As a result, neither meet the recommendations set out in NICE guidelines for children and adult diagnosis. Commissioners across health and social care in Children's and Adult services are engaged within the working groups to develop a transparent diagnostic pathway inclusive of multi-agency support in pre and post diagnosis, and to realise the best use of resources.
- 4.12.2 **Children** - The children's diagnosis service has undergone a review and has received extra resources to support the reduction of the waiting list. They are currently working towards a 12 week waiting list as opposed to 12 months.
- 4.12.3 Re-think have been approached to support the NAPB to provide clear and transparent pathways that are understood by people with autism, their parents/carers and professionals alike. It is the intention to hold:

- a) A workshop for professionals to obtain a clear understanding of the young people ASD pathways throughout Norfolk
 - b) A workshop for people who have used those diagnosis pathways and pre and post support to share what has worked well and what has not worked so well
- 4.12.4 **Adults** – Asperger’s Service Norfolk, delivered in partnership by Norfolk Community Health and Care and Asperger East Anglia is funded by the five CCGs and the Council. Currently there is a four-year waiting list, additional resources are being sourced to reduce it.
- 4.12.5 The Adult diagnostic service currently diagnose Asperger syndrome only. The Joint Strategic Commissioning Committee (JSCC) and the Council agreed to fund the service for an additional year, while commissioners develop a new model to meet the future needs of diagnosis in addition to modelling what a pre and post diagnostic support pathway looks like for implementation April 2020.
- 4.12.6 This will be informed through engagement with people accessing those services and professionals such as GP’s seeking to access the current pathway.

5 Financial Implications

- 5.1 Funding will be required for the continued activity and support of the All Age Autism Partnership Board and co-production workshops and has been incorporated into the overarching service budget.
- 5.2 The review of existing autism commissioning arrangements, including diagnostic pathways that include pre and post diagnosis support such as social care delivered by the Council, may result in proposed additional spend
- 5.3 Workforce development training for Council staff is required and will be delivered in 2019.

6 Issues and risks

- 6.1 **Risk:** The autism diagnosis service is due to finish in March 2019. An offer to extend the existing contract has been proposed to the existing provider, Asperger Service Norfolk (ASN) delivered in partnership by NCHC and Asperger’s East Anglia. Contingency plans are being implemented to ensure that the service remains available including spot purchasing of services.

7. Recommendations:

Adult Social Care Committee is asked to:

- a) **Acknowledge the work undertaken in the continued development of Norfolk All-Age Autism Partnership Board, Norfolk All-Age Autism Group and the working groups in place to undertake priority work identified**
- b) **To consider the contribution from services across the Council to the strategy**
- c) **Agree to receive the local all-age autism strategy that will be informed by the completion of the National Autism Self-Assessment (completed 14 December 2018) with a co-produced all age strategy available March 2018**

Officer Contact

If you have any questions about matters contained or want to see copies of any assessments, eg equality impact assessment, please get in touch with:

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