

Report title:	Autism Strategic Update
Date of meeting:	17 July 2018
Sponsor (H&WB member):	James Bullion (Executive Director Adult Social Services)
<p>Reason for the Report</p> <p>The Health and Wellbeing Board is asked to acknowledge progress and support the work proposed to support the development of an All Age Autism Partnership Board, the identified workstreams to support the development of a local All Age Autism Strategy.</p> <p>Report summary</p> <p>This report updates the Health and Wellbeing Board on progress to support the implementation of the Autism Act (2009) National Autism Statutory Guidance (2016) and Strategy 'Think Autism' over the past 6 months.</p> <p>It provides the Health and Wellbeing Board with information on work 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. Including the development of an All Age Autism Partnership Board and the wider engagement of people with autism to inform the development of a local partnership All Age Autism Strategy.</p> <p>Action/decisions needed:</p> <p>The HWB is asked to:</p> <ol style="list-style-type: none"> 1. Acknowledge the development of The Norfolk All Age Autism Partnership Board 2. Acknowledge and support the development of the working groups in the undertaking of priority work 3. Agree to receive the Norfolk All Age Autism Strategy that will be informed by the completion of the National Autism Self-Assessment (2018) 4. Support the undertaking of a community engagement exercise that will seek to obtain the life experiences of people with autism and their families living in Norfolk further inform the priorities of a local autism strategy. 	

1. Background

- 1.1 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.
- 1.2 To support this undertaking local areas have been encouraged have a local Autism Partnership Board (or appropriate alternative) and undertake the completion of a

National Autism Self-assessments that enables the local partnership to demonstrate progress and identify priorities to form a local autism plan.

- 1.3 The National Self-Assessment provides DH with the local area evidence required to undertake the assurance function placed upon them by the Autism Act 2009.
- 1.4 The Health and Wellbeing Board is named within the national Autism Strategy as the local strategic partnership to be sighted on progress locally.
- 1.5 With regards to children and young people the autism statutory guidance reminds local authorities and education of the requirements of the Children and families Act and the SEND 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).
- 1.6 Papers on the Adult Autism agenda have not previously been presented to the Health and Wellbeing Board, although it has been identified as a priority for members of the Health and Wellbeing Board and there has not been a local autism plan or strategy to date.

2. Content

- 2.1 The current prevalence of people with autism in the population is approximately 1%. In Norfolk that equates to a predicted population of 5080 adults aged (16-64) in 2017 with an expected population growth to 5211 by 2035 (Pansi 2016) of which it is predicted that 2826 will be aged 65 +. In 2016 there were an estimated 2491 children and young people with Autism in Norfolk.
- 2.2 Currently the data collection of people living in Norfolk with a diagnosis of autism across the age range is unreliable with pockets of information and no one single place that collects the information. Equally current data recording systems do not consistently collect information on autism. The most reliable source of information is via the DfE statistical returns; for pupils at SEN Support this is via individual school 'Special Educational Needs register' and directly from the Local Authority for pupils with Education Health & Care Plans.
- 2.3 The current Norfolk pupil population is a total of 119,959 and within this there are a total of 18,589 who are identified with SEN. Within this overall SEN cohort, identifies that there are 6.5% of primary age pupils with ASD (compared to 6.5% nationally) and 7.8% of secondary age pupils with ASD (compared to 9% nationally), as at the end of the academic year 2016/17 (note: the figures for the current academic year will be available after the summer break when national tables are updated).
- 2.4 This highlights an average of 7.15% of the SEN cohort identified with ASD a total 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 approx 295 pupils.
- 2.5 Autism is not a mental illness or a learning disability, it is a developmental spectrum condition often described as ASD or ASC, people with autism will share at a level personal to them difficulties in social functioning including communication, comprehension and imagination. People with autism can also experience heightened sensory experiences with lighting, sound and touch all impacting upon someone's daily living experience. The impact of Autism upon an individual is unique and will be helped or hindered by their personal and environmental circumstances.

Asperger Syndrome also sits within the Autism spectrum in which the person does not have a learning disability or is above average intelligence.

- 2.6 People with Autism are likely to have additional needs sometimes including a learning disability, that is estimated at approximately 45%, and/or mental health conditions such as depression or anxiety effecting up to 70% of the population (Lei et al 2014). People with autism are also at risk of health inequalities contributed by fixed dietary routines, with primary care issues increasing in severity due to potential aversion in visiting the GP resulting of the challenges their autism may bring.
- 2.7 Norfolk's ambition has been to develop an all age strategic approach in the delivery of the autism agenda with the development of an all age autism strategy to inform the vision and the priorities in the delivery of improved life outcomes and opportunities for people with autism, and their parents and or family carers.
- 2.8 It meets the Health and Wellbeing Board strategic priorities considering the health and wellbeing needs of people on the autistic spectrum and their families through:
- Understanding what prevention means
 - Providing accessible help and support at an earlier stage before problems become acute or get worse
 - Reduce of inequalities in health and wellbeing
 - Narrowing the gap in life expectancy between the most and the least deprived people in Norfolk.
 - Designing and delivering Integration where appropriate and applicable
 - Partners working together to provide effective, joined up services
- 2.9 Over the past 6 months significant steps have been taken to realise the ambition. This has been in part by increasing the engagement with the autism community people with autism not currently engaged in social care services without a Learning Disability and who have been articulating their dissatisfaction of the progress that had been made.
- 2.10 A series of community engagement 'conversations' have taken place which resulted in the co-production of the terms of reference and forming of the Norfolk All Age Autism Partnership Board that sat for the first time on the 30th April 2018. The meeting is representative of family carer, parent representation in addition to people with autism, including the co-chair. People were invited to express an interest to sit on the Board and were voted in by their peers. The All Age Partnership Board members also include the Police, Adult and Children Social Care, Education, Health Commissioners and Providers in addition to not for profit voluntary providers.
- 2.11 A review of the current activity in the delivery of the Autism Statutory Guidance and Autism Strategy has been undertaken that has identified 4 key work priorities for delivery that sit across the whole age agenda, which have been approved by the All Age Autism Partnership Board.
- 2.12 Work is underway through the development of co-production working groups in the following areas that include;
- Interagency Workforce and Training Plan**
- 2.13 Includes the development and delivery of a training programme for social care assessors and the wider workforce to support improved applied delivery across adult

social care 3 conversations assessment process. This will also include children social care training programme.

- 2.14 It will include an extended multi-agency review of the current training available within organisations such as health, police and education in the forming of a multi-agency workforce and training plan.

Engagement

- 2.15 Includes the development of an engagement tool that will be adapted to meet the accessibility needs and language to reach the all age autism community living in Norfolk including parents and carers. This will provide an insight into the lives of people with autism against the priorities of the Autism Strategy, the Care Act and Preparing for Adulthood. The engagement exercise will broaden the offer for participation in addition to inform the priorities of the strategy including accessing a diagnosis and pre and post diagnostic support. In addition to accessing and retaining employment opportunities, housing and accessing their local community resources. The engagement exercise will be adapted to enable as many people as possible to participate.
- 2.16 This includes a survey, paper versions, discussions within existing peer support groups and services and schools for example.

We would welcome the support of the Health and Wellbeing board in the promotion of the engagement exercise

- 2.17 In-addition the continuation of the wider autism community partnership groups that will take place across Norfolk 4 times a year will enable people to share their experiences on an ongoing basis.

Data

- 2.18 Work is underway to determine what recording systems are currently in place to determine autism. The intention is 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.

Diagnostic Pathways

- 2.19 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. Both have as a result not met the recommendations set out in NICE guidelines for children and adult diagnosis. Commissioners across health and social care in children and adult services are engaged within the working groups in order to develop a transparent diagnostic pathway inclusive of multi-agency support in pre and post diagnosis, and in order to realise the best use of resources.
- 2.20 **Children** – The children diagnosis service has undergone a review and has received extra resources to support the reduction of the waiting list.
- 2.21 **Adult** – Funded by the 5 CCGs the Adult diagnostic service currently diagnosis Asperger syndrome only. A paper has gone to the Joint Strategic Commissioning Committee (JSCC) to obtain the support in reviewing the current model and make recommendations for the future.
- 2.22 The priorities being delivered by the working groups will inform the development of the Norfolk All Age Autism Strategy and the activity over the next 3 years. In

addition, it will place Norfolk in better position for the undertaking of 2018 National Autism Self-Assessment due to be issued early summer to local authorities and the local area partnerships for completion and return in the autumn.

Officer Contact

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