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## Health and Wellbeing Board

17<sup>th</sup> October 2018

Report of the Interim Corporate Director of Children, Education and Communities

### All Age Autism Strategy Update

#### Summary

1. This paper looks at the priorities identified in the All Age Autism Strategy 2017-2021, progress to meeting this and on-going issues. The key areas that are focused on are:
  - Inclusive communities
  - Assessment and diagnosis
  - Transitions
  - Training / education
  - Employment
  - Parent / Carer support
2. There is significant public concern about the waiting time for autism diagnosis, the need for clarity about the pathway and lack of support during that time.
3. The paper asks the Health and Wellbeing Board to endorse the update on the All Age Autism Strategy action plan (contained within the All Age Autism Strategy).

#### Background

4. Between 1% and 1.5% of the population nationally are estimated to have autism. About 206,000 people live in York which means there are likely to be over 2,000 people living in York with autism, either diagnosed or undiagnosed. Autism is a lifelong condition which can be diagnosed at different points in a person's life depending on how it is affecting their daily lives.

5. There are increasing numbers of children and adults diagnosed with autism and consideration about how to meet their needs in education, health, employment and inclusion in society has become a focus of concern. For example there has been 112% increase in the identification of autism as the primary need for children in the schools census in the last 4 years (annex 1 refers). This rise is predicted to increase. Applefields Special School have 50% of their cohort with a diagnosis of autism for the first time from September 2018.
6. Nationally, we know that 70% of children and young people with autism develop mental health problems and parents report long waits for intervention from Children and Adolescent Mental Health Services (CAMHS).
7. Only 16% of adults with autism in the UK are in full-time paid employment, and only 32% are in some kind of paid work.
8. A large consultation event was held in March 2016 to consider what the key areas of focus should be. The vision for the All Age Autism Strategy 2017 – 2021 is:  
  
*‘to make York an autism inclusive City where people with autism have the same opportunities as everyone else.’*
9. The strategy makes it clear that the approach we wish to promote in York is an inclusive one, where the skills and abilities of all are valued. The principles of the strategy are:
  - People with autism and their families and carers are at the centre of everything we do
  - Focus on people’s strengths to overcome barriers
  - Guidance, information and support are easily available
  - The right support at the right time
  - Increased awareness of autism across the city
  - Living in your community and being included
10. The All Age Autism Strategy was completed in August 2017, with the Autism Joint Strategic Needs Assessment (JSNA) finalised in October 2017. The Integrated Commissioning Group then held a deep dive looking at a number of case studies to consider the issues around support for children and young people further in November 2017.

11. Additionally delivery of the All Age Autism Strategy was discussed at a Health and Wellbeing Board Workshop in September 2018; this paper brings an update on the development of an action plan to meet the needs of children, young people and adults with autism.
12. There are six areas of focus identified in the All Age Autism Strategy and the update will consider each of these in turn.
  - Inclusive communities
  - Assessment and diagnosis
  - Transitions
  - Training / education
  - Employment
  - Parent / Carer support
13. The issues for the focus around parent/ carer support is considered within each of the other 5 sub groups.

### **Main/Key Issues to be considered**

#### Inclusive communities

14. The priorities identified through the engagement events and outlined in the autism strategy were as follows:
  - Increase public awareness in the community
  - More social groups
  - More choice of activities across the City, including non specialist places
15. The following progress has been made towards these priorities:
  - A new social group called York Autism Meeting (YAM) for adults with autism meets monthly and is run by someone with Aspergers and for those who want to get to know others in a similar situation. The Autism Strategy Group has supported a bid to the Big Lottery to facilitate the development of the YAM group to become more sustainable to meet the needs of the growing numbers of those wanting to use the group.
  - Living Autism delivers Autism Champions Courses to tourist centres such as the Minster to become more autism-inclusive. Autism badges are given to the organisations demonstrating a level of awareness. Follow up 6 months after training has

shown the awareness has been cascaded and embedded. Below is an article from The Press on the difference the course has made already in York.

<http://www.yorkpress.co.uk/news/16344388.yorks-tesco-askham-bar-makes-strides-to-become-autism-friendly/>

- Live Well York (LWY) (formerly known as Connect to Support) has had a soft launch and provides extensive information on what is available locally to support adults in the community. Links to the Local Offer are included.

### Assessment and diagnosis

16. The identified priorities include

- reducing the waiting time
- the need for information and support about the diagnostic process whilst waiting for an appointment
- Psychological support to manage anxiety

17. The following progress has been made towards these priorities:

- The under 5s pathway managed by the Community Paediatric clinic at York Hospital is running at capacity but does not have a waiting list. There is a high conversion rate of around 93%. This is to be expected, as the young children referred in will be showing very clear characteristics of autism.
- 5-18 years diagnosis pathway
- Demand for autism assessments is high and continues to increase. Since 2015/16 referral numbers have increased from 88 to 261 in 2017/18, and 143 between April and September 2018. This has placed significant pressure on Tees, Esk and Wear Valleys NHS Foundation Trust (TEWV) in managing the assessment and diagnostic pathway. Current (September 2018) information is that 197 children and young people are waiting for an assessment. The average waiting time from referral to specialist full assessment was 47 weeks. This has been an increasing trend. However, the conversion rate is 54%; this means that a very high number of children and young people are being referred for assessment whose needs do not reach the international ICD-10 threshold for a formal diagnosis. This is a matter that requires a clearer

understanding across schools, education support as well as health.

- In the current year, NHS Vale of York Clinical Commissioning Group (CCG) has committed £120K one-off funding for additional autism assessments. TEWV has committed £50K recurrently for the autism assessment pathway and staff are in post as at the beginning of October 2018.
- Also, there is now an improvement plan with TEWV to consider the issues around management of the pathway: TEWV has reviewed, and continues to keep under review its screening processes to ensure that children who are highly unlikely to receive a positive diagnosis are signposted at the earliest opportunity. TEWV expects the waiting time, and numbers waiting to reduce by the end of 2018/2019.
- A workshop looking at the assessment pathway and information is planned for December 2018.
- NICE guidance for autism assessment is that the assessment should be within 13 weeks of referral.
- There is increasing public concern about the waiting time and what support is available during this time. A current petition entitled York Autistic Assessment Crisis has almost 400 signatures and calls for reduced waiting and better support during the waiting times.  
<https://you.38degrees.org.uk/petitions/york-autistic-assessment-crisis>.
- There is also concern that support is provided dependent on gaining a positive diagnosis.
- There is intensive support through FIRST, jointly funded between the Council and health, for those with autism or learning disability who exhibit very challenging behaviours. This very successful service offers intensive support to hold families and placements and prevent young people having to go into residential placements. The programme is currently being extended to include therapeutic short breaks as part of the new Centre of Excellence.
- Admission into tier 4 inpatient units have reduced significantly in the last year following the implementation of the local Crisis Team. However, there is no data on how many admissions concern children and young people with a diagnosis of autism. In 2017/18 there were 49 admissions overall from Vale of York. Currently there are 5 young people from Vale of York CCG in in-patient (diagnosis not known).

## Adult Autism Assessment

18. The adult autism and ADHD assessment and diagnostic service is provided across North Yorkshire and York by the Tuke Centre.
19. The current contract with The Tuke Centre allows for 36 referrals a month. However there has been an increase with 146 referrals in May to July 2018, 90 of which were for autism. The largest age group is 20-29 year old males. There have been 252 individuals screened since January 2016 with 160 (77%) having had a positive diagnosis. Currently the average waiting time is 13 months to screening (where someone may be rejected at this point) and from screening to outcome an average 3 months
20. Key challenges are waiting times, with no clear pathway post diagnosis in terms of support. An assessment for social care support does not guarantee eligibility for social care support and we need to ensure that progress is made in developing community led support initiatives.
21. Local Area SEND Inspections: each local area is being inspected by Ofsted and Care Quality Commission (CQC) re: special educational needs and disability. Each area is due to be inspected before April 2019. The focus is on assessment, outcomes and experience of children, young people and their families.
22. The inspections have consistently highlighted local areas who are not meeting the NICE guidelines for times from referral to full assessment for autism. Each local area has been required to provide a written statement of action based on this alone, or on a combination of issues. York, like the majority of areas is not currently meeting NICE guidelines.

## Training / education

The identified priorities include:

- Provision of primary Enhanced Resource Provision for children with autism
- More autism awareness in mainstream schools.
- Offer alternative educational provision for young people who cannot access mainstream school.
- Specialist training packages working with local employers, including the police.

- Peer awareness in education and training settings.
- Reduced waiting time to attend ASCEND course (a course from parents with newly diagnosed children)
- More post 16 work placements.

23. The following progress has been made towards these priorities:

- The Communication and Interaction Enhanced Resource Provision has been running from September 2017 and includes children with autism
- The specialist teaching team run two courses a term for teachers – Autism Awareness and Understanding Behaviour.
- Trained autism champions are in every secondary school and 17 primary schools.
- Ascend courses for parents of recently diagnosed children – now offer six per annum but there is still a waiting list.
- The specialist teaching team have increased capacity to work with doubled numbers of children and young people with autism in schools, providing support, training, guidance and some interventions
- There is a growing need for the Safe Base for young people with high anxiety unable to attend school
- York Learning currently has 90 students per year and offers work learning packages. York Learning have worked with Danesgate to support 4 students to access post 16 learning , as they would find college environment too difficult
- Blueberry Academy and Project Choice continue to offer a range of internships for students with autism or learning disabilities which can act as a springboard to work opportunities.

### Transitions

24. The identified priorities include

- Joint commissioning 0-25 to reduce the number of changes with a parallel reduction in stress and anxiety for all concerned
- A wider knowledge of existing Autism provision within schools/education/community and increased provision 19.
- Specialist Autism workers within our Community Support/Community Short Breaks teams /Work with York

- Information has been improved through the development of new leaflets and continued through events. The What's Next Booklet, the Specialist Careers Advisors guidance and the Pathway for Students post school with an Education, Health and Care Plan moving on with their education have all improved information available this year. The Annual Opportunities Fair was held in July. Workshops and multiple information stands provided the young people and their families opportunities to find out what is available in York post school
- A new provision for young people 19+ with profound and multiple learning difficulties, including those with complex autism has opened at Askham Bryan College September 18.
- Work still has to be done re developing autism specialism within community support

### Employment

25. The identified priorities include
- Identify clear and realistic pathways to work
  - Improved information on jobsearch, work benefits
  - Participate in careers / jobs fairs
  - Increase access to supported employment schemes/providers
26. Prospects, Recruitment, Opportunities for young autistic adults (PRO Autism) have run workshops to support understanding of issues and identification of solutions with St John's University and North Yorkshire branch of the Chartered Institute of Personnel and Development (CIPD) to improve employment opportunities for young autistic adults leaving further and higher education.
27. Various programme are supporting adults with autism into work including the
- Proof of Concept Project run by United Response and commissioned by the Department for Work and Pensions (DWP) and City of York Council (CYC)
  - Work & Health Programme run by the Department for Work and Pensions (DWP).
  - DWP Specialist Employability Support (SES) programme
  - Move Forward, delivered by I2I and Ixion



28. All programmes provide personal support to identify employment goals, match skills to work that's available and get training to find work.
29. Access to Work, the grant to cover cost of support in the work, continues to be promoted. Disability Confident is a scheme that is designed to help employers recruit and retain disabled people and people with health conditions for their skills and talent.

### **Key decisions**

30. The action plan for the All Age Autism Strategy is being updated to include:
  - Promote Live Well York and Local Offer to ensure information about what is available in York is accessible
  - Provide information on autism pathway with expectations of waiting times and sign posting to support if needed
  - Review children's autism assessment pathway with aim of improving conversion rate to minimise delays in understanding need and to use resources efficiently. Develop an action plan on how to reduce waiting times.
  - Re commission adult autism diagnosis service with follow up support for those diagnosed
  - Publish an updated All Age Autism assessment pathway
  - Detail what support is available to families while waiting during assessment pathway and promote with local practitioners.
  - Living Autism to continue to deliver Autism Champions Courses with follow up to ensure autism friendly approaches are embedded
  - Provide/promote autism training for front line staff who see public in West Offices/short break workers, WWY staff
  - Promote guidance and information about supported work internships/work opportunities

- Consider joint commissioning of services through the Integrated Commissioning Group to support moving into adulthood.

## **Consultation**

31. A large consultation event was held in March 2016 to consider what the key areas of focus of the strategy should be. Parents, young people and adults with autism, professionals and support workers all attended. The Integrated Commissioning deep dive held in November 2017 with a wide range of participants including parents, education, social care, health and police, voluntary sector. The York Parent Carer Forum AGM September 2018 included some consultation on what key priorities were for families. The overwhelming response was that there was concern over lack of capacity in a number of health services and a perceived inequality of service, based on those who complained most gaining a quicker response.
32. Engagement events re adult autism pathway were held in July 2018 as part of the re-procurement of adult diagnostic service.

## **33. Options**

34. The Health and Wellbeing Board are invited to endorse the approach and detail of the All Age Autism Strategy action plan. Priority should be given to detailing information around the autism assessment pathway, support during waiting time and an action plan to become closer to NICE compliance.
35. Secondly, all Agencies to commit to roll out autism training with front line staff which will support greater understanding of need and reduce barriers to participation. Proactively promoting information about the Local Offer (0-25) and Live Well York (adults' information) will enable children, young people and adults with autism to know what is happening/available in York. This will enable York to be more inclusive and become an autism friendly city.

## **Analysis**

36. Endorsing the action plan will ensure progress on this sensitive agenda is maintained. Focus on assessment of autism will support a response to the petition and avoid need for written statement of action in the impending Local Area SEND inspection.

## **Strategic/Operational Plans**

37. The All Age Autism strategy is aligned to the priorities in the council plan and Children and Young People's Plan and the NHS Vale of York Clinical Commissioning Group's (CCG) Strategic Plan.
38. This report updates the Health and Wellbeing Board on the All Age Autism JSNA and Strategy.

## **Implications**

### **Financial**

39. Should the Health and Wellbeing Board endorse compliance with the NICE guidelines there would be financial implications due to the need to increase capacity in the assessment pathway for children and adults.

### **Human Resources (HR)**

40. There are HR implications if all agencies endorse training of front line staff and providing sufficient capacity to

### **Equalities**

41. Endorsing the action plan of the All Age Autism strategy supports a proactive approach to disability equality, breaking down barriers to inclusion.

### **Legal**

42. There are no legal implications

### **Crime and Disorder**

43. There are no crime and disorder implications

### **Information Technology (IT)**

44. There are no IT implications

### **Property**

45. There are no property implications

### **Other**

46. There are implications to the impending Local Area SEND inspection. All other recent Local Area inspections have been required to write a written Statement of Action if they are not NICE compliant re the number of weeks between referral and assessment for autism.

### **Risk Management**

47. There is a risk that following a Local Area SEND inspection there will be a requirement to provide a Written Statement of Action re autism waiting times as above.

### **Recommendations**

48. The Health and Wellbeing Board are recommended to endorse the All Age Autism Strategy action plan to maintain progress to meeting need and proactively promoting and autism inclusive city.
49. The Health and Wellbeing Board are recommended to promote autism awareness training to all agency front line staff

### **Contact Details**

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Report of the Interim Corporate Director  
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**Report  
Approved**

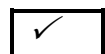


**Date** 03.10.2018

**Specialist Implications Officer(s)** None

**Wards Affected:**

**All**



**For further information please contact the author of the report  
Background Papers:**

All Age Autism Strategy  
All Age Autism JSNA

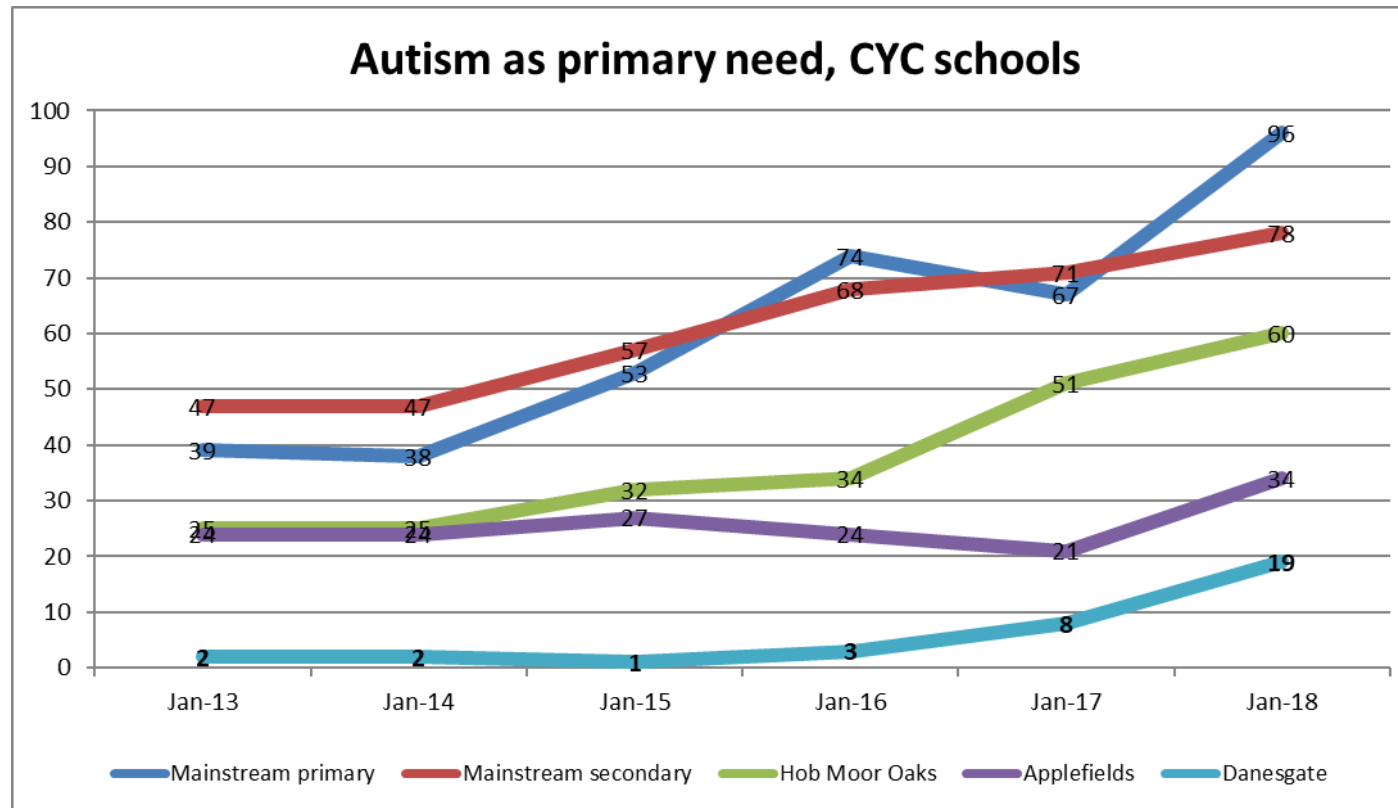
## **Annexes**

**Annex 1:** Autism as primary need in CYC schools

Annex 1

**Autism as primary need in CYC schools** (from Schools Census)

Type of School	Jan-13	Jan-14	Jan-15	Jan-16	Jan-17	Jan-18
Mainstream primary	39	38	53	74	67	96
Mainstream secondary	47	47	57	68	71	78
Hob Moor Oaks	25	25	32	34	51	60
Applefields	24	24	27	24	21	34
Danesgate	2	2	1	3	8	19



<b>Comparison Year of Year</b>	<b>Jan-13</b>	<b>Jan-14</b>	<b>Jan-15</b>	<b>Jan-16</b>	<b>Jan-17</b>	<b>Jan-18</b>
Autism as primary need	135	136	170	203	218	287
% increase from prev. year		1%	25%	19%	7%	32%
% increase from Jan 2013		1%	26%	50%	61%	113%

