North Yorkshire County Council

Health and Wellbeing Board

30 September 2015

Strategy for meeting the needs of children, families and adults with autism in North Yorkshire 2015-2020

Report of the Corporate Director – Health and Adult Services and Director of the Partnership Commissioning Unit

1.0 Purpose of report

- 1.1 This report seeks to gain Health and Wellbeing Board's approval for the strategy for meeting the needs of children, families and adults with autism in North Yorkshire 2015-2020 to be published in October 2015.
- 1.2 This report also seeks Health and Wellbeing Board's approval to publish a brief document specifically for people with autism and the wider public stating the overall ambitions for supporting people with autism in North Yorkshire up to 2020.

2.0 Issues

- 2.1 This strategy has been written by the lead officers for autism in Children and Young People's Services (CYPS) and Health and Adult Services (HAS) within North Yorkshire County Council and colleagues from the Partnership Commissioning Unit (PCU) on behalf of the four North Yorkshire Clinical Commissioning Groups. The draft strategy is available at Appendix 1. The strategy was approved by the autism project board on 9 September 2015.
- 2.2 Public consultation has taken place on the draft strategy between 21 May and 11 September 2015. There has been an online consultation questionnaire and five consultation events held in Harrogate, Skipton, Selby, Scarborough and Northallerton. The feedback has been positive and constructive and has informed some significant revisions to the strategy. A document detailing the key themes that were raised during the consultation has been attached to this report at Appendix 2. There has also been feedback from the Scrutiny of Health Committee which has fed into the revised strategy. Key themes to emerge were in relation to; support for people with autism and their families; assessment and diagnosis, raising awareness and training, information and signposting, employment and education, supporting people with autism at key stages in their life, and working together.
- 2.3 A key piece of feedback, raised a number of times during the consultation was that people want a strategy document that states the key ambitions on autism

in North Yorkshire, in a short and accessible format. The project board discussed this issue on 9 September and wish to recommend to the Health and Wellbeing Board that an additional document is produced. This document will be no longer than 4 pages in length and people with autism will be invited to work with an internal design team comprising NYCC and PCU officers. This document will be the strategy document and will include a vision for the work on autism in North Yorkshire between 2015-2020. It will be published via a public launch event in November/December 2015.

- 2.4 It is therefore proposed that the consulted draft strategy (Appendix 1), which is, in effect the market position statement and core to the strategy, be kept in Word format and published with a statement that it becomes an accompanying document to a proposed shorter and more accessible autism strategy.
- 2.5 The strategy needs approval for publication by the Health and Wellbeing Board in order to ensure the strategy is published to its deadline of end of October 2015.
- 2.6 An implementation plan will be produced in the first instance for the period 1st November 2015 to 31st March 2016. It will be made up from outstanding items from the current but separate children's and adult plans which will be brought together under one banner. In January 2016 the first annual implementation plan for April 2016 to March 2017 will be produced taking the new strategy forwards. This will be reviewed and refreshed on an annual basis for the duration of the strategy. It is the intention to update the Health and Wellbeing Board on progress after a six-month period.

3.0 Policy Implications

- 3.1 This strategy will drive the work on autism in North Yorkshire for the forthcoming five-year period between 2015-2020.
- 3.2 The strategy will encompass people with autism of any age and their families/carers. It recognises that there is a range and severity of need. The strategy has been and will continue to be informed by legislation, a number of national priorities and best-practice models.

4.0 Financial Implications

- 4.1 Approval has been given for costs for the consultation, design and publication of the strategy to be jointly shared between the partner organisations/directorates.
- 4.2 There is no further Government funding at this time for autism and all services/support identified within the strategy will have to be resourced from existing budgets within the Clinical Commissioning Groups and NYCC.

5.0 Legal Implications

- 5.1 The national strategy for adults with autism in England, 'Fulfilling and Rewarding Lives' (2010) and its subsequent review 'Think Autism' (2014), gave the NHS, local authorities and other partners statutory duties with regard to improving the lives of those living with autism. The national autism strategy sets out a clear directive for change to ensure that those with autism are included in society and supported to lead full and rewarding lives.
- 5.2 The strategy will help to meet statutory duties around autism for North Yorkshire's Health and Wellbeing Board.

6.0 Consultation Undertaken and Responses

- 6.1 Over 90 people attended the five consultation events about the strategy and there were 31 completions of the consultation questionnaire. There were also several email responses. All of the consultation feedback was taken into account during the final revisions to the strategy and the proposal to create a stand-alone document specifically for people with autism and the wider public is as a direct result of consultation feedback.
- 6.2 A "You said, we did" document will be produced to accompany the publication of the strategy which will detail the changes made to the strategy as a result of feedback.

7.0 Impact on Other Services/Organisations

- 7.1 HAS, CYPS and the PCU are joint partners in this strategy and, therefore, will be required to put actions into place to fulfil the requirements of the strategy. For example, the PCU has recently concluded a procurement on behalf of the four North Yorkshire Clinical Commissioning Groups for a local diagnostic service for autism and ADHD for adults in North Yorkshire.
- 7.2 The District Councils and North Yorkshire Police have agreed to endorse the strategy and there will be work required with those organisations and others, such as Job Centre Plus to ensure multi-agency involvement in the further development of support for people with autism in North Yorkshire.

8.0 Risk Management Implications

- 8.1 Key partners have jointly contributed to the strategy to the agreed timescale. Regular editorial meetings take place between NYCC and PCU staff and Project Board meetings are held every three months to monitor progress.
- 8.2 The strategy will help to meet statutory duties around autism for North Yorkshire's Health and Wellbeing Board. There would be strong challenges from national and local bodies and individuals should this project not be delivered.

8.4 This project will not result in cashable savings, but ensuring appropriate and effective support is provided for children, young people and adults with autism is likely to reduce the incidence of crises, reduce the breakdown of school placement, necessity for mental health involvement and the need for residential care or supported living.

9.0 Equalities Implications

9.1 The draft Equalities Impact Assessment (EIA) is attached at Appendix 4 for approval. The EIA will be made available online alongside the published strategy in October 2015. A draft Easy Read version of the strategy has been produced and is attached at Appendix 5.

10.0 Recommendation(s)

- 10.1 That the consulted draft strategy (market position statement) for meeting the needs of children, families and adults with autism in North Yorkshire 2015-202 including the easy read version, Policy framework document, and the equality impact assessment be approved by the Health and Wellbeing Board to be published on 1 October 2015.
- 10.2 That the Health and Wellbeing Board grant approval for a 4-page strategy document designed by people with autism and NYCC/PCU staff to be published which gives accessible and clear information about North Yorkshire's ambitions for autism between 2015-2020.

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16 September 2015

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List of appendices

- Appendix 1 draft autism market position statement
- Appendix 2 key themes raised through consultation
- Appendix 3 Autism policy framework document
- Appendix 4 Equalities Impact Assessment
- Appendix 5 Easy read version of the autism market position statement

Autism Strategy consultation events Main feedback by theme

<u>Diagnosis</u>

- Improve diagnosis for girls with autism
- Improve post diagnostic services from health to include supporting young people in understanding the diagnosis, sleep difficulties, eating difficulties, sensory needs
- The diagnostic process does not always consider behaviour within the home
- There is not always a key worker this would be helpful
- The links between diagnostic services and schools are not good
- Diagnosis is not open or transparent enough
- There needs to be a follow up visit after families have had time to digest the diagnosis information.
- An information booklet or website would be useful that explained what to expect in relation to a diagnosis and what to do next.

Awareness raising

- Needs to be about awareness, knowledge and understanding awareness is not enough.
- Knowledgeable teachers, support staff, GP's, social care staff, hospital staff, mental health services, provider services are needed that really understand autism and know how to work effectively with children, young people and adults with autism.
- GP's need to know about the referral pathway.
- There is a need for parent training/support at different stages through the child/young person or adults journey. This training needs to offer tools and strategies for dealing with issues such as behaviour that challenges.
- There needs to be increased understanding around girls with autism and children with autism who are looked after or adopted.
- More needs to be done to raise awareness of higher functioning children with autism and the subtle difficulties that they are experiencing.
- Provider services need training in autism.

Information and signposting

- An online hub would be useful that contained information and a chat forum.
- A single database of children, young people and adults with autism would be helpful for informing people of events and activities.

- Information on interventions and strategies need to be available to families as well as schools.
- An information pack post diagnosis is not enough.
- A single point of contact would be helpful for advice, guidance and signposting.
- Clear support plans need to be developed and maintained for children, young people and adults with autism to support information sharing.
- Literature is needed for children, young people and adults with autism, their siblings and the extended family. Library hubs would be good that include fiction and reference books.
- There is a lack of information for services about how to support children, young people and adults with autism.
- The NYCC website needs to be more user friendly for those with autism.

Employment and education

- Primary to secondary transition is difficult for many families.
- Schools need to make more reasonable adjustments to make the environment and curriculum work for children and young people with autism.
- Transition from education to employment and careers advice for young people with autism is poor.
- Peers need to be better informed in relation to autism.
- There is a need to measure the number of people with autism in paid employment.
- Employers need to be better informed about autism and there needs to be job coaching and employment support for young people with high functioning autism (HFA).
- There needs to be more of an incentive for employers to recruit people with autism.
- NYCC and the NHS should provide supported internships for people with autism and lead by example.
- Schools need more knowledge of autism interventions.
- Job centre plus need a better understanding of autism.
- Schools should be more accountable and transparent in demonstrating how they are using SEN funding to support individuals.
- Schools need to value the parent's knowledge of their child and of autism and work with the family not against them.
- Schools need to develop their knowledge of the C&FA and the EHCP process.
- Consideration needs to be given to how the LA can achieve engagement from all schools even those that are resistant.
- There is a need for autism champions in every school.

• The strategy needs to consider how best to support parents seeking a good education establishment for their child.

Support for people with autism and their families

- Parent support needs to be strengthened this could be facilitated by parents for parents.
- Groups for parents have been invaluable but funding cuts puts these groups under threat.
- There is a lack of social activities for children, young people and adults with autism.
- There is a need for positive handling training for parents of children with autism.
- Families need support with planning for the future as they get older.
- When a person disengages with services the family still require support
- Families do not feel well supported
- The local authority needs to ensure that carers assessments are available for parents of children and young people with autism
- There is a need to develop safe environments within the community for people with autism
- Crisis support needs to be available 24 hours a day, 7 days a week
- The emphasis needs to change from supporting children and families at crisis point to early intervention and better understanding and acceptance

Working together

• There needs to be collaboration with the police and district councils to develop skills in children with autism in relation to stranger danger, road safety, health eating etc.