

# **CABINET Subject Heading:** Draft All Age Autism Strategy **Cabinet Member:** Councillor Jason Frost Councillor Robert Benham SLT Lead: Barbara Nicholls/Tim Aldridge Report Author and contact details: Gerry Flanagan Interim Commissioning Programme Manager gerry.flanagan@havering.gov.uk The Strategy is in line with Council **Policy context:** Objectives relating to Communities. There are no financial implications Financial summary: Yes because Is this a Key Decision? Significant effect on two or more Wards When should this matter be reviewed? Autumn 2021 **Reviewing OSC:**

## The subject matter of this report deals with the following Council **Objectives**

Individuals and Children & Learning

Communities making Havering	[x]
Places making Havering	[x]
Opportunities making Havering	[x]
Connections making Havering	[x]

#### **SUMMARY**

This report summarises the draft All Age Autism Strategy. It sets out the background to the Strategy, both locally and nationally; the Strategy contains a high level action plan which has been developed in conjunction with some stakeholders and makes recommendations for the next steps.

## RECOMMENDATIONS

#### Cabinet is recommended to:

- 1) Authorise the commencement of a consultation process on the content of the draft All Age Autism Strategy set out at Appendix 1.
- 2) Note that the results of the consultation will be referred back to Cabinet for determination of the final version of the Strategy in the Autumn 2019

## REPORT DETAIL

## **Background**

- 1) Autism is a disorder which affects how a person makes sense of the world, processes information and relates to other people. It is known as a spectrum disorder or spectrum condition because the difficulties it causes can range from mild to severe, and these affect people both to different degrees and in different ways. Nonetheless, all people with autism share three areas of difficulty:
  - Social communication difficulty using and understanding verbal and non-verbal communication, such as gestures, facial expressions and tone of voice
  - Social interaction problems in recognising and understanding other people's feelings and managing their own; and
  - Social imagination problems in understanding and predicting other people's intentions and behaviour and imagining situations beyond their own experiences.
- 2) People with autism may experience over or under-sensitivity to sound, touch, taste, smell, light or colour. Many, but not all, people with autism may also have other conditions such as attention deficit hyperactivity disorder (ADHD), a learning disability or dyspraxia.

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- 3) Although the exact number of people with autism is not known, it is thought that approximately 1% of the population of the UK has some form of autism. In Havering this means that approximately 2,560 people are likely to have autism, although the real numbers may well exceed this.
- 4) The Joint Strategic Needs Assessment (JSNA) (2018) indicated that:
  - There is an increasing demand for specialist help and schooling for children with Autism
  - b. Increases of 40% were seen in children with Autism between 2012 and 2015, numbers of children diagnosed with autism spectrum disorder (ASD) in the primary school population are expected to double over a 5 year period (from 2015 to 2020)
- 5) An Autism Strategy was produced in Havering in 2017, and was based on priorities outlined in national policy and statutory guidelines together with local needs. The local strategy focused on adults with High Functioning Autism who have average or above average intelligence (i.e. not those people who have both learning disability and autism) including those with Asperger's Syndrome. This was because there are already services in Havering for people who have autism and a learning disability.
- 6) National and statutory policy and guidelines (i.e. The Autism Act 2009, National Autism Strategy for Adults, Fulfilling and Rewarding Lives, and its update Think Autism 2014) concentrated predominantly on the needs of adults. Whilst the local 2017 strategy acknowledges the need for adult services to work in partnership with children's services (to learn from the work they have already done and to smooth the path of people in transition from children's to adult's services) it was influenced in the main by the national and statutory guidelines emphasis on adult services.
- 7) Since completion of the local strategy in 2017, there has been recognition that the needs of children and young people with Autism should be prioritised alongside those of adults and work began to develop an all age strategy for Havering.

## **National Position**

- 8) Havering's position mirrors that of other areas and also national policy. Late in December 2018, as part of the Government's review of the National Autism Strategy, plans were announced to introduce an updated national autism strategy, which will cover people of all ages in England. Ministers acknowledged that far too many children on the autism spectrum are currently held back from achieving their potential. They have accepted that a national approach is needed to improve the support that is offered to children and their families.
- A national consultation has just been launched in order to gather evidence to inform a new national strategy; it is currently expected that the new national strategy will be published late in 2019; ideally to coincide with the

10<sup>th</sup> anniversary of the passing of the original Autism Act. A further national consultation has just closed relating to training for staff working in health and social care and how to ensure that they understand the needs of people with a learning disability and/or autism and have appropriate skills to provide the most effective care and support.

- 10) Early indications of the Government's review and intentions for a new revised national strategy are that it will be looking at the following areas:
  - joining up health, care and education services to address autistic children's needs holistically
  - developing diagnostic services to diagnose autism earlier, in line with clinical guidance and reduce waiting times
  - improving the transition between children and adult services so that young people with Autism are supported to reach their full potential as young adults, and, in some cases, ending inappropriate reliance on in-patient hospital care
  - improving understanding of autism and all its profiles, including recently identified forms such as pathological demand avoidance (PDA)
  - encouraging public sector bodies to make more effective use of their equality duties in order to improve access to services for people with autism
  - continued emphasis on employment and developing pathways into employment for people with autism
- 11) The NHS has, in recent months, published its 10 year plan. Supporting people on the autism spectrum or with learning disabilities is one of the 4 clinical priority areas identified in the NHS long-term plan. Other specific issues in the 10 year plan relating to autism are:
  - Renewed focus on reducing waiting times for diagnostic and specialist services for children and young people
  - By 2023/2024 a 'digital flag' will exist in the NHS patient record for all people with a known learning disability or autism
  - Learning disability and autism awareness training will be mandatory for all NHS staff

#### **Local Context**

- 12) A self-assessment (SAF) on Havering's progress in respect of the National Autism Strategy was completed in late in 2018; this concentrated mainly on adults and services for them, with some limited reference to carers and young people (mainly transition). This identified some positive areas in Havering:
  - Havering's Autism Partnership Board and involvement of adults with autism (but need to appoint a person with autism as co-chair)

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- Post diagnostic support for people with learning disabilities (but not for adults more generally)
- · Some data is kept and used for planning
- Some good preventative and low level support for people who don't meet eligibility under the Care Act 2014
- Good examples of work done within acute hospitals
- Some positive local innovations;
  - Development of shared lives model of support
  - Development of a framework to ensure sufficient supported housing for vulnerable young people and adults. Some emerging evidence of cross borough work (with Barking & Dagenham and Redbridge)
  - The Havering Autism Hub
  - Funding for NELFT linked to Transforming Care Programme (TCP) work to avoid unnecessary admission of people with autism to hospital
  - The education service has a dedicated team of advisory teachers and assistants who work with schools advising and supporting children with autism in their education placements
- 13) The Havering High Needs Review and Strategy (2017) identified children with autism as a priority area and a new Primary Additional Resourced Provision for ASD is opening in 2019 with a further 2 in primary and 1 in secondary schools planned for 2020. There is also a new Special Free school being planned for 2021.
- 14)A joint OFSTED/Care Quality Commission inspection of SEND provision in Havering in 2018 highlighted the issues which the borough does well in respect of children and young people with disabilities as well as areas for improvement:

## Things Havering does well:

- Arrangements to identify the needs of children and young people who have SEN and/or disabilities have improved and services are having a substantial impact on the outcomes for children and young people.
- There is a broad range of training for staff that is matched to the needs of children and young people identified in school. This includes for example training in autism spectrum disorder – as a result skills and expertise of practitioners is improving.
- Havering has established a Young Advisers Group, to find out what young people who have disabilities think about their lives. This helps Havering to better understand what is important to young people who have disabilities in Havering.

#### Areas for improvement:

Co-production is not strong enough. As a result, parents feel they
have little input into the support provided for their children. They lack

confidence in decisions about the commissioning of new services. Some parent groups view consultation meetings with the local area as 'tick-box' exercises. As a result, parents are losing confidence in the process.

- The contribution that social care professionals make to EHC plans is limited.
- The local offer is not used effectively enough; typically parents and young people were not aware of its existence.
- Some parents and carers of children and young people who have autistic spectrum disorder have articulated their concerns about a lack of post-diagnosis support. This is not compliant with guidelines and results in children and young people having identified needs which remain unmet.
- Havering is not aspirational enough about the future outcomes of children and young people. For example, there is no strategy to support young adults into employment.
- 15) The work in producing the SAF also identified a number of areas which required further attention and improvement:
  - A need for more consistent recording of data in Havering.
  - The need for more consideration in public services to be made regarding reasonable adjustments.
  - Transition processes and clearer pathways for young people moving into adulthood.
  - Planning for specific populations in Havering.
  - Better recording of hate crime.
  - Lack of an overall Havering wide partnership training plan, uptake of training by certain groups and awareness of autism.
  - Pathways for diagnosis not widely known and in some cases there are long waits for diagnosis.
  - Post diagnostic support for people / signposting for those not meeting eligibility under the Care Act 2014.
  - Carers' needs and accessible information.
  - Difficulty to engage all stakeholders in Havering autism still seen as an issue for social care, education and specialist health.
  - Some employment initiatives were evident but at a very early stage.
  - Inconsistent reference to employment in EHCP plans.
  - Families feeling excluded from planning.
  - · Access to housing and housing advice.
- 16) Whilst not specific areas picked up by the SAF, other issues felt locally by people and families that need further attention are:
  - Community safety, anti-bullying work and teaching people life skills to avoid being intimidated and becoming victims of coercion and control.

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 Transport issues – partially linked to safety but also linked to life skills and increased independence.

## Key Themes of the Strategy

- 17) The draft strategy indicates a number of priority areas for action, together with a high level action plan. The key areas are:
  - Planning
  - Involvement, information and access
  - Health care
  - Employment
  - Training and awareness
  - Housing
  - Improved pathways
  - Transport, keeping safe and life skills

## **Next Steps**

- 18) It is acknowledged there has thus far been limited involvement from stakeholders in identifying the priority themes, however the draft strategy has been developed with input from:
  - Members of the Autism Partnership Board
  - Feedback from the High Needs Review
  - Feedback to complete the Self Assessment
- 19) As there has not yet been a full consultation with all stakeholders regarding the strategy, then families, children and young people and adults with autism (as well as other stakeholders) need to have a full opportunity to have their say on both the areas of priority identified and the key actions to achieve those aims.
- 20) The draft strategy indicates that consultation should take place over a 3 month period starting in May 2019. The consultation will make use of meetings/forums with groups of interested parties (families and people with autism), questionnaires and surveys, and discussions with key partners.
- 21) There are a number of other considerations that are key to fully implementing the strategy and require both further discussion and work in moving forward to develop a new all age autism strategy:
  - a) Development and implementation of an all age strategy may be led by social care but will require sign up across the Council and other public sector bodies in order for the strategy to be implemented.
  - b) Some national initiatives are linking Autism and Learning Disability. Whilst the reasons for this are understandable, people with autism are anxious that the work done in recent years to separate the two may be in danger of being eroded.

- c) The work on the Transforming Care Programme (TCP) has led to better links between commissioners across the 3 boroughs and CCG; this potentially could provide a good foundation for developing the autism agenda across the wider footprint, not just of Havering but the 3 boroughs of Havering, Redbridge and Barking and Dagenham
- 22) The areas identified for local improvement are not at odds with either the issues identified by Government as part of its review and those picked up by the SAF and other work undertaken in Havering; these are themes that will form part of the revised all age strategy. Once consultation (including an equalities impact assessment) is complete, it is intended that the revised all age strategy is signed up to by key statutory partners including the Council's Cabinet, by autumn 2019.

## **REASONS AND OPTIONS**

## Reasons for the decision:

- 23) Autism is a condition which affects both adults and children and can lead to individuals feeling they are unable to fully meet their potential. Autism is sometimes referred to as the unseen disability it can be, and often is as disabling to people as any other form of visible disability but because people may not appear to have a disability, their condition and its impact upon their lives can be easily overlooked and worse ignored.
- 24)Local authorities are required to produce a strategy for people with disabilities and to work with partners to support people to lead fulfilling lives, additionally all public bodies have a statutory duty to ensure, through use of their powers and responsibilities under Equality Legislation, to make reasonable adjustments to their services in order to improve access.
- 25)In order to ensure that children, young people and adults with autism in Havering have the best chance of leading full and fulfilling lives the Council has strategically taken the view that the development and implementation of an all age strategy is the most effective way to do so and that full Council support and that of its key strategic partners is key to ensuring this.

## Other options considered:

- 26) **Do nothing –** There is already in existence an adult autism strategy and other strategies e.g. the High Needs Strategy to address some of the issues relating to children and young people. This option is not recommended because:
  - a) There is not sign up to the adult strategy across all stakeholders,

- b) There have been difficulties in engaging with some key stakeholders both within and beyond the Council, and the High Needs Strategy only addresses issues relating to education,
- c) Havering may be required to produce an all age strategy at some stage in the coming years as work relating to the emerging new national strategy indicates that that will be an all age strategy and will presumably include some indication of the direction of travel local areas should take.
- 27) Only produce a new Children and Young Persons Autism Strategy This option is not recommended:
  - a) As above, Havering may be required to produce an all age strategy at some stage in the coming years as work relating to the emerging new national strategy indicates that that will be an all age strategy and will presumably include some indication of the direction of travel local areas should take.
- 28)Only produce a strategy relating to what the Council's role is relating to people with autism This option is not recommended:
  - a) National guidance currently suggests developing strategies relating to local areas, not just local Councils,
  - b) People rely on other public sector services in addition to those provided and accessed via the Council.

**IMPLICATIONS AND RISKS** 

## Financial implications and risks:

29) None

## Legal implications and risks:

- 30) There is no duty to prepare an Autism Strategy, although central Government is required to do so by virtue of section 1, Autism Act 2009. The Department of Health has issued statutory guidance to Local Authorities in March 2015, "Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy" which sets out guidance amongst other things:
  - On local planning and leadership in relation to the provision of services for adults with autism,
  - Preventative support and safeguarding in line with the Care Act 2014,
  - Employment for adults with autism.
- 31) The draft Strategy appears consistent with this Guidance.

32)Whenever a public body commences consultation then it must to do so meaningfully. It must provide sufficient time and information for consultees to respond intelligently. Then the final decision can only be taken after conscientious consideration of the responses to the consultation.

## Human Resources implications and risks:

33) Training and raising awareness in Children and Adult Social has been identified in the report. If additional resources are required to manage the outcomes in the strategy, the service will review and manage capacity issues and expectations.

## **Equalities implications and risks:**

- 34) The Public Sector Equality Duty (PSED) under section 149 of the Equality Act 2010 requires the Council, when exercising its functions, to have due regard to:
  - (i) the need to eliminate discrimination, harassment, victimisation and any other conduct that is prohibited by or under the Equality Act 2010:
  - (ii) the need to advance equality of opportunity between persons who share protected characteristics and those who do not, and;
  - (iii) foster good relations between those who have protected characteristics and those who do not.
- 35)Protected characteristics' are: age, sex, race, disability, sexual orientation, marriage and civil partnerships, religion or belief, pregnancy and maternity and gender reassignment.
- 36) The Council is committed to all of the above in the provision, procurement and commissioning of its services, and the employment of its workforce. In addition, the Council is also committed to improving the quality of life and wellbeing for all Havering residents in respect of socio-economics and health determinants.
- 37) Autism is a form of disability that is not limited to any one particular section of Havering's population. It impacts on people with all of the identified protected characteristics. However an Equality and Health Impact Assessment (EqHIA) is not being completed at this stage. This is for the following reasons:
- a) Cabinet are only being asked to approve that the draft strategy is the subject of a full and wide consultation
- As part of the consultation it will become clear how specifically the publication of an all age strategy will impact on people who share protected characteristics
- c) A full EqHIA will be completed as part of the submission of the complete strategy in the autumn of this year

# Appendix 1 - The Draft Autism Strategy

BACKGROUND PAPERS

None