

## **Committee: Health and Wellbeing Board**

**Date: 26 June 2018**

Agenda item:

Wards: All

### **Subject: Merton Autism Strategy 2018-2023 and Action Plan**

Lead officer: Dr Dagmar Zeuner, Director of Public Health

Lead members: Cllr Tobin Byers, Cllr Kelly Braund

Forward Plan reference number:

Contact officer: Julia Groom, Consultant in Public Health; Dr Sally O'Brien, Public Health Registrar

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#### **Recommendations:**

- A. To approve the Autism Strategy 2018-2023.
  - B. To endorse the Strategy Action Plan.
  - C. To agree to champion the ambition to make Merton an autism-friendly borough, and in particular to support the objective to improve autism awareness in the wider population which was highlighted as a priority in engagement on the Autism Strategy.
  - D. To agree the proposed governance arrangements for the Strategy.
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#### **1. PURPOSE OF REPORT AND EXECUTIVE SUMMARY**

- 1.1 The purpose of this report is to inform the Board about the development of the Merton Autism Strategy 2018-2023. It is also to seek approval for the final Strategy and Action Plan and request that members of the Board champion opportunities promote awareness of autism and work towards Merton becoming an 'autism-friendly' borough.
- 1.2 The report sets out drivers for the development of the Strategy; outlines the six priority themes of the strategy and summarises the findings of a public engagement period. It highlights key deliverables set out in the strategy action plan; updates on progress of the redesign of the 0-19 support and diagnosis pathway; and sets out proposed governance arrangements and next steps.  
A summary of the strategy is on p.5-8 set out in Appendix A.

#### **2. BACKGROUND**

- 2.1 Autism is a life-long condition affecting about 1 in every 100 people. It affects how people see, hear and feel the world. Everyone with autism will experience it differently. Autism is a spectrum of different needs, which means people with autism are on different points on the spectrum and affected in different ways.
- 2.2 It is estimated based on prevalence figures that there are about 540 children and young people and 1,200 adults with autism in the borough. Demographic data suggests that the number of people with autism is increasing. In Merton there has been an increase in children with autism recorded as their primary type of educational need; 407 CYP in 2017, an increase of 60% from 2013. As the population grows older the number of adults with autism is projected to rise, increasing by 14% to reach approximately 1,570 adults in 2030, although

local trends indicate this may be higher. This implies there will be an associated increase in need for care and support for adults with autism in Merton over time.

- 2.3 Feedback from stakeholders including service providers, voluntary organisations, people with autism and families and carers have told us they want to see improvements in support and services locally.
- 2.4 There are statutory guidance and legal duties for local authorities and the NHS, along with evidence based quality standards. Public sector services are all facing financial pressures and need to work in partnership to ensure that resources are used effectively.
- 2.5 In response to these factors, the London Borough of Merton (LBM) and Merton NHS Clinical Commissioning Group (MCCG) have developed an Autism Strategy, working in collaboration with a range of partners. The strategy takes a life-course approach and encompasses children, young people and adults, taking into account the needs of families and carers.

### 3. DETAILS

- 3.1 The Merton Autism Strategy sets out a vision to ‘develop an autism-friendly borough in which people with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them’.

The strategy document sets out the following background: drivers for change (p.10), national policy and guidance (p.13-14), information on our population (p.14-16), a detailed description of our current services and access to support (p.17-25), and summary of stakeholder feedback (p.25-26).

#### **Strategy Priorities**

- 3.2 The Strategy includes six priorities and for each sets out evidence for change, where we are now, where we want to be and how we will get there (p.30-46):
  - *Awareness training and support for staff and services:* this priority includes the general population as well as those working with people with autism having a better awareness and understanding. This means understanding the specific strengths of people with autism as well as having an awareness of challenges they may face and counteracting unhelpful stereotypes and prejudices.
  - *Recognition, support, referral and assessment:* we know that the earlier autism is identified the better the outcomes. Early support, diagnosis and assessment of needs can offer an understanding of why a child or adult is different from their peers. Improving the support and diagnosis pathway for 0-19 year olds as well as having clear protocols for adult diagnosis is a priority.
  - *Involving and supporting people with autism:* people with autism will have different needs at different times of life and key to this strategy is having access to the right support at the right time. We want people with autism to be fully involved in their care and able to participate equally, including in education, employment and leisure.
  - *Preparing for adulthood:* this priority is a recognised challenge. Although the majority of young people with autism will not need specialist services as an adult, they may need support as in developing independence, such as

learning additional life skills, seeking opportunities for further education, apprenticeships and employment.

- *Think family –involving and supporting families and carers:* families and carers value existing support but felt strongly that there should be a better continuum of support and more parenting programmes, particularly for those with children over 8 years.
- *Access to information:* Access to comprehensive information about local services is important to support making informed choices. Building on and strengthening the 'local offer' for children, young people and adults is important.

The Strategy is attached as Appendix A and an easy read version at Appendix B.

### **Public engagement**

3.3 Initial stakeholder engagement in 2017 included a survey of stakeholders; a workshop involving 35 partners; presentations and discussions at community and voluntary sector groups and forums involving people with autism; parents and carers. This helped shape the draft strategy and agree the six priorities.

3.3 In February–March 2018 a public engagement on the draft strategy took place. This comprised of an on-line survey and paper easy-read survey; engagement through facilitated feedback sessions including adults and young people with autism; parents and carers; and professionals.

A total of 146 participants engaged in the feedback process as individuals and/or part of group feedback, including 19 people with autism and 45 parents/carers.

Key issues from the engagement which have been incorporated in the final strategy include:

- Strong support for the vision, aims and priorities within the strategy. However there were also significant concerns that there was not strong enough commitment to achieving the aims and no additional resources, which meant a risk that it would not result in tangible improvements for people with autism.
- Strong feedback that awareness training for staff and other residents was fundamental to achieving the aim of becoming an 'autism-friendly' borough and should be given higher priority.
- Consistent feedback that improvements were needed to improve early intervention and support, access to diagnostic services and availability of post-diagnostic support, and support for parents and carers.
- The need to prioritise services which are inclusive for people with autism and enable social participation and independent living.
- The need to listen to parents and carers, whilst ensuring that the voice of people with autism is at the forefront of decision-making.

Further details of the public engagement are set out in Appendix D.

### **Action Plan**

3.4 An outline action plan has been developed for the life of the strategy. This has aimed to respond to concerns that the draft strategy did not give strong

enough commitments by highlighting which actions will be prioritised for delivery in the first year. These include:

- Action 1.1: Improve the local training and awareness offer, including delivering a training programme for CYP workforce.
- Action 2.1: Redesign and improve the assessment, diagnosis and support pathway for 0-18 year olds.
- Action 2.2: Raise awareness of the diagnostic pathway for adults.
- Action 2.3: Promote autism champions in all education settings.
- Action 3.1: Improve customer journey in adult health and social care for adults with autism.
- Action 3.2: Ensure people with autism are actively involved in co-designing and delivering services.
- Action 3.3: Improve employment opportunities for people with autism.
- Action 3.4: Improve opportunities for people with autism to participate socially.
- Action 3.5: Increase the number of places within specialist and additionally resources educational provision.
- Action 4.1: Improve the quality of transition assessments.
- Action 5.1: Identify resources to increase provision of parenting programmes.
- Action 5.2: Ensure families and carers are involved in the co-design and delivery of services.
- Action 6.1: Improve quality and accessibility of information available to people with autism and their families/carers.

3.5 Other actions set out in the plan will be developed over the life of the strategy and this action plan will be reviewed and updated on an annual basis.

3.6 Lead officers for each priority will develop milestones and relevant partnership groups with monitor delivery. It is important that delivery of the Action Plan builds on existing infrastructure and resources, and identifies all opportunities to lever in additional resources in order to scale up or enhance services.

The Action Plan is attached as Appendix C.

### **0-18 Assessment support and diagnosis pathway**

3.7 A key priority in the strategy is redesigning and improving the assessment, diagnosis and support pathway for 0-18 year olds. It is widely recognised that the current diagnosis pathways do not meet the needs of residents and this was a consistent theme in the public engagement on the strategy.

3.8 The CCG has invested short term funding to reduce waiting times within current services. The CCG are leading on the co-production of a new pathway in the short and longer term. There is a commitment to retain open access for diagnostic assessment, provide help and support earlier in the pathway, and reduce waiting times for children and young people.

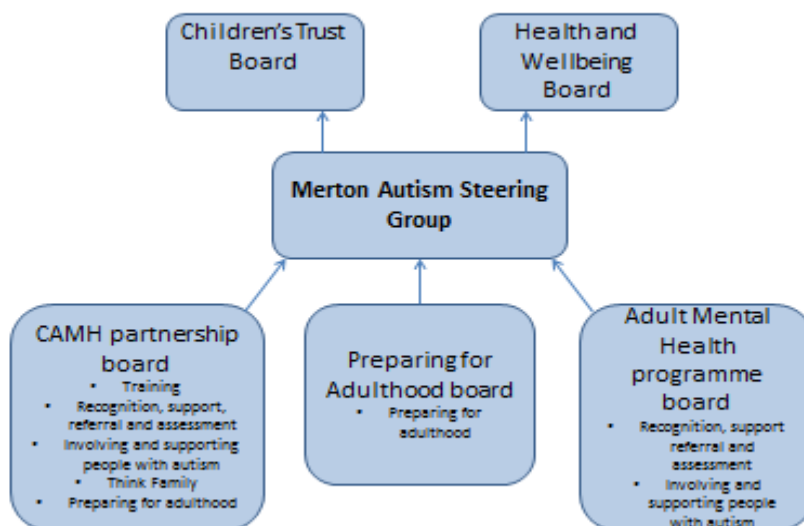
3.9 As part of this we will continue to engage children and young people, parents and carers and professional stakeholders, including community paediatrics and CAMHS, who deliver the current 0-5 and 5-18 diagnostic services respectively.

## Governance

3.7 It is proposed that:

- Progress on delivering this action plan is to be monitored through existing partnerships (including the CAMHS Partnership and Preparing for Adulthood Partnership and Adult Mental Health Programme Board).
- In the first year an Autism Partnership steering group will be established to provide leadership and oversight, this will report to the Children's Trust Board and Health and Wellbeing Board.
- There is a commitment in the strategy to engaging people with autism and parents/carers in the steering group and delivery of the strategy which will require support. Talk Autism/Kids First have already identified parents/carers who may wish to participate and people with autism who participated in discussion groups have expressed an interest in continuing to be involved.

Fig.1: Proposed governance:



## Next Steps

- Work is already underway to deliver priority objectives in the action plan, including children and young people assessment and diagnosis pathway redesign.
- It is proposed that the first Steering Group takes place in September 2018.
- Members are asked to champion the commitment to making Merton an autism-friendly borough and in particular to support the objective to improve autism awareness in the wider population which was highlighted as a priority in public engagement.

**4. ALTERNATIVE OPTIONS**

None

**5. CONSULTATION UNDERTAKEN OR PROPOSED**

Significant public engagement has been undertaken in the development of the strategy including pre-strategy stakeholder engagement and public engagement on the draft strategy.

A summary is set out in the Strategy document p.25-26. Further details are set out in Appendix D. Merton Autism Strategy Public Engagement Feedback report.

**6. TIMETABLE**

The strategy is for 2018-2023. The action plan will be reviewed annually.

**7. FINANCIAL, RESOURCE AND PROPERTY IMPLICATIONS**

The strategy recognises the financial constraints of both NHS and local authority partners and has been developed on the basis that it will be delivered within existing resources and the expectation is for better use of existing resources aligned to need through better collaboration between partners.

It is important that the delivery of the action plan builds on existing infrastructure. It also includes commitments for partners to enhance or scale up delivery by seeking opportunities to lever additional resources to the borough.

**8. LEGAL AND STATUTORY IMPLICATIONS**

In 2014 an updated national strategy for adults 'Think Autism' was published. Statutory guidance from the Department of Health was published in 2015. This contains a number of duties on local authorities and the NHS. Further details: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/422338/autism-guidance.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/422338/autism-guidance.pdf)

The Merton Autism Strategy and action plan contributes to supporting implementation of the national strategy for adults.

**9. HUMAN RIGHTS, EQUALITIES AND COMMUNITY COHESION IMPLICATIONS**

Based on the evidence that many people with autism are socially and economically disadvantaged, the strategy is likely to have a positive impact on equality through seeking to address the needs of residents with autism.

An equality analysis detailed opportunities to further promote equality. A summary is set out in the strategy document p.28.

**10. CRIME AND DISORDER IMPLICATIONS**

People with autism may be witnesses or victims of crime and at risk of bullying and intimidation. People with autism also appear to be over-represented in the

criminal justice system nationally and guidance highlights the importance of ensuring the needs of people with autism are met in all custodial settings.

The strategy includes theme 1: awareness training and support for staff and services, which was highlighted in the public engagement as a priority for public services and includes an action to work with the Police and work with partners to deliver awareness training to relevant staff groups.

**11. RISK MANAGEMENT AND HEALTH AND SAFETY IMPLICATIONS**

N/A

**12. APPENDICES – THE FOLLOWING DOCUMENTS ARE TO BE PUBLISHED WITH THIS REPORT AND FORM PART OF THE REPORT**

- a. Merton Autism Strategy 2018-23
- b. Merton Autism Strategy –Easy Read
- c. Merton Autism Strategy Action Plan
- d. Merton Autism Strategy Public Engagement report

**13. BACKGROUND PAPERS**

None

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