

Cabinet	 TOWER HAMLETS
19 September 2017	
Report of: Denise Radley, Corporate Director, Health, Adults and Community	Classification: Unrestricted
Autism Strategy for Adults 2017-22	

Lead Member	Councillor Denise Jones, Cabinet Member for Health and Adult Services
Originating Officer(s)	Karen Sugars, <i>Divisional Director Integrated Commissioning</i> Barbara Disney, <i>Service Manager - Strategic Commissioning</i> Jack Kerr, <i>Strategy Policy & Performance Officer</i>
Wards affected	All wards
Key Decision?	Yes
Community Plan Theme	A healthy and supportive community

Executive Summary

- 1.1 Autistic Spectrum Disorder (ASD) is a lifelong developmental disorder, characterised by impairments in social interaction, social imagination and communication. Recent estimates suggest that approximately 1.1% of the population have Autistic Spectrum Disorder.
- 1.2 The attached “2017-22 Autism Strategy for Adults” represents the first strategy of its kind in Tower Hamlets. The strategy sets out how local services will support autistic adults¹ over the next five years, and how we will collectively meet national policy requirements in relation to adults with autism.
- 1.3 The strategy is primarily made up of eight priorities to be worked on over the next five years. These priorities are as follows:
1. Help autistic people to feel like part of their community
 2. Help autistic people access good quality health and social care services
 3. Support young people with autism to transition into adulthood
 4. Raise people’s skills and knowledge in relation to autism
 5. Help autistic people to find and keep work
 6. Help autistic people to live in good quality housing that meets their needs
 7. Reduce and improve autistic people’s interaction with the criminal justice system

¹ The phrase “autistic adults” or “autistic people” is being used in preference to “adults with autism” or “people with autism” in line with feedback from autistic people.

8. Help those who care for friends and family with autism
- 1.4 The strategy proposes that an Autism Partnership Board be established in Tower Hamlets to oversee the delivery of the strategy over the coming years.

Recommendations:

The Mayor in Cabinet is recommended to:

1. Agree to the Adults Autism Spectrum Disorder Strategy at Appendix 1.

1. REASONS FOR THE DECISIONS

1.1 Rationale for developing an Autism Strategy:

- 1.1.1 National Autism Strategy: A local Autism Strategy will ensure we are meeting the requirements of the national Autism Strategy and accompanying statutory guidance. This strategy was first published in March 2010 following the Autism Act in 2009, and was most recently updated in January 2016. Statutory guidance was produced in March 2015.
- 1.1.2 Self-assessment: A local Autism Strategy will enable issues identified in our local self-assessment to be addressed. Tower Hamlets has taken part in a number of self-assessments to evaluate our progress on implementing the national autism strategy for adults. The last self-assessment that was completed in October 2016 highlighted a number of areas for improvement.
- 1.1.3 Legislation: A local Autism Strategy will help ensure we are meeting the requirements of the 2014 Care Act in relation to adults with autism. For example, duties around the provision of universal information and support to residents and the need for services to work cooperatively with one another are all applicable to people with autism.
- 1.1.4 Transforming Care Programme: A local Autism Strategy will ensure we are working in accordance with the Transforming Care Programme. This programme arose from the 2011 Winterbourne View case, and is focused on developing services and support for people with a learning disability and/or autism who display behaviour that challenges. It sets out an expectation that more community services be developed and with a view to reducing the number of adults with challenging behaviour in in-patient facilities.
- 1.1.5 Demand: A local Autism Strategy will help address the issue of an anticipated increase in demand for autism-related support. Staff feedback is that the number of children and young people with a diagnosis of autism has seen a 150% rise in recent years. The local authority and partner organisations need to anticipate and address a potential increase in demand for support as this cohort reaches adulthood.

- 1.1.6 Joint Strategic Needs Assessment: A local Autism Strategy will enable the needs of adults with autism as identified in the Joint Strategic Needs Assessment to be addressed. A JSNA Factsheet on “Autism Spectrum Disorder” is currently being finalised. Findings highlight a number of areas for improvement, which can be addressed through the strategy.
- 1.1.7 People with a learning disability: Having a separate Autism Strategy will ensure that the needs of autistic adults are not “lost” within learning disability support provision. People with autism can sometimes be categorised as having a “learning disability”, particular in terms of the services they come into contact with. A significant proportion of autistic adults will also have a learning disability, but this will not be true in all cases.

2. ALTERNATIVE OPTIONS

- 2.1 No other options have been considered as the Autism Act (2009) places a statutory requirement for Local Authorities and Health to put in place a local plan for Adults with Autism Spectrum Disorder.

3. DETAILS OF REPORT

3.1 Scope of the strategy

- 3.1.1 The attached 2017-22 Autism Strategy for Adults aims to ensure that we are making strides towards the national vision of autistic adults. This is as follows:

“All adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents.”

- 3.1.2 Whilst the “Autism Strategy for Adults” has been primarily developed by the Adult Services Directorate, it is presented as a partnership strategy as we recognise that the needs of autistic adults cut across services and are not exclusive to adult social care. It is a partnership strategy that will primarily be held by the local authority and Clinical Commissioning Group.
- 3.1.3 The strategy has a focus on adults but not autistic children. Evidence suggests that the number of children and young people diagnosed with autism has grown rapidly in recent years, and according to staff feedback, autism is now one of the three most common long-term conditions affecting children. The needs of this group will instead be addressed in a planned strategy for children and young people with Special Educational Needs or Disabilities (SEND). This will place a real focus on early intervention to help children and young people with Autism. The new SEND strategy is scheduled to be presented to Cabinet for final sign off in January 2018

3.1.4 The lifespan of the strategy is five years rather than the originally proposed three, in recognition of the fact that many of the objectives are longer-term aims.

3.1.5 In order to fully realise the strategic vision of this strategy, additional resources may be required initially, for such things as increased awareness across the whole system. At the moment there is no dedicated budget specifically available to adults, whose primary care need is Autism, other than that for the Diagnostic and Intervention Service, currently funded through the Better Care Fund. This is unlikely to be more than £50,000 but will be identified by the Autism Steering Group. Funding for this has been identified from the new adult social care monies.

3.2 Consultation feedback in developing the strategy

3.2.1 The “Autism Strategy for Adults” was primarily developed over November and December 2016. The development of the strategy was overseen by representatives from adult social care, public health and the Clinical Commissioning Group. Further consultation activity has taken place in

3.2.2 The aspiration was to fully co-produce the “Autism Strategy for Adults” with autistic people. This aspiration has not been fully realised, however the strategy has been driven by the views and experiences of autistic adults as much as possible. There have been key barriers in relation to co-producing the strategy: Firstly, the current design of services means there is no easy way to get in contact with autistic adults², and secondly, a number of service users with Autism are non-verbal and difficult to engage³. The timescales involved in developing the strategy have also limited the opportunity for coproduction. However meaningful engagement has taken place through a number of consultation exercises. This includes:

- Two all day workshops held with autistic adults and their carers. This was widely advertised through a press release to numerous local media outlets, on twitter and a specially designed poster sent to our adult social care providers. The workshops were attended by 10 people with Autism and some carers
- An online survey⁴ was widely advertised to numerous local media outlets, on the Councils social media pages and the link sent to Tower Hamlets adult social care providers. Hard copies of the survey were also made available and sent out. In total the survey was completed by 26 people.
- A focus group was held with Tower Hamlets inter faith group to discuss the draft strategy and to collect feedback.

² For example, there is no one list of contact names and addresses for adults who have received an autism diagnosis, and no one service regularly attended by a cross-section of autistic adults.

³ For example, we attempted to engage service users at Tower Projects First Start day centre which is exclusively used by autistic adults. However almost all services users are non-verbal and were not able to be effectively engaged.

⁴ A hard copy of the survey was also available and was sent out to groups who requested it. However no hard copy survey responses were received.

- Feedback and evidence has been gathered by a wide range of professionals including those in the health, employment and criminal justice sectors.
- Tower Hamlets Learning Disability Partnership Board and staff from Tower Hamlets Autism Diagnostic and Intervention service have provided feedback to the strategy.

3.2.3 The feedback gathered from these key stakeholders helped to shape the aims and objectives of the strategy. Further consultation and engagement activity carried out in May 2017 has proved that people endorse the strategies and its eight identified objectives for people with Autism. People were particularly keen on the idea of staff training to raise awareness of autism. All of the messages we received during the consultation period have been incorporated into the Autism Strategy for Adults. Key messages from the Consultation include:

General

- People support the idea of staff training on autism and feel it is needed.
- Some people find the label “autism” useful. Others do not, and would actively seek to avoid it. As a result, there was a divide in opinion when it came to “Autism Alert” cards: Some people feel strongly that they would be useful. Others feel strongly that they do not want to use them. Those who like the idea of an Autism Alert card would also like to see IT systems “flag” the issue that a person has autism, so that they do not have to repeatedly explain themselves when contacting public services.
- Some autistic people may actively seek to avoid interaction with services (e.g. primary care). This could be due to previous negative experiences. This can cause problems in getting a diagnosis, and getting post-diagnostic support. Have to think through how to get support to these people.
- People would like to see form-filling that is brief and to the point

Health

- People suggested the idea of having annual Health Checks with GPs
- People suggested that autism awareness training be provided to health professionals, but also frontline staff (e.g. GP receptionists)
- People would like to see:
 - The offer of home visits from GPs or community nurses for autistic people who cannot leave their homes
 - Forms that are brief and to the point
 - The offer of GP appointments that are longer than 10 minutes
 - The offer of GP appointments at quieter times
 - The offer of seeing a consistent GP
 - A reduction in waiting times at the GPs
 - GPs using visual diagrams (e.g. body diagrams, or a picture of the GP) to assist with communication
 - Visitor parking permits for appointment times
 - A write up of appointments so that either themselves or their family can refer to it later

- Better use of the Hospital Passport book
- Better support for carers

Housing

- People like that they can reapply for housing on medical grounds
- People would like planning to consider:
 - Access to space (e.g. gardens) for those who are housebound
 - The risks posed by having an open-plan kitchen and living room (it can be easier for autistic people to access kitchen hazards)
 - The risks posed by having balconies in high-rises
 - The risks posed by having locks that are easy to unlock (it can lead to people wandering)
 - Cluttered pavements that can be difficult to navigate through.
- Would be good for people to “make an effort” with their neighbours in order to get support from their communities.

Crime

- There was mention that the British Transport Police are good – people had good experience of them interacting with people with autism
- People would like to see:
 - The system providing quiet and calm spaces for autistic people
 - Criminal justice system staff using communication aids
- People raised the question as to when challenging behaviour becomes criminal behaviour
- People mentioned “mate crime” as an issue facing some autistic people.
- People would like to see quicker access to their family or carers

Social Care

- A number of people recounted that they had received help whilst children, but that this had ended at the point of reaching adulthood. There was a feeling that resources are stretched and that little is available.
- People would like adult social care to consider:
 - Providing people with a consistent Social Worker
 - Staff sending a write-up of meetings after they take place
 - The autism diagnostic service in Tower Hamlets providing support on a longer-term basis
 - Providing support to combat social isolation for autistic people
 - Supporting an occasional informal coffee morning in a safe, quiet space
 - A drop-in service provided in a less formal way may be useful

Society

- It would be good to work with local shops so that staff are more aware of how to deal with autistic people and challenging behaviour.
- A peer-led group may be useful to establish.

Employment

- JET Tower Project employment services was praised by a few respondents to the survey as having a real expertise in supporting autistic people with work
- People would like to see:
 - More work placements and employment opportunities for autistic people
 - The opportunity for timely reviews with both parties (employer/employee), separately and together.
 - More CV preparation and interview training, more mentors
 - Support for autistic adults on how to manage social situations at work
 - Application forms that are as brief as possible
 - Support with using public transport, recognising that people may struggle with employment if the travel there is stressful.
 - An ongoing support group led by autistic adults who are successfully employed and can share their positive experiences
- One person mentioned a service in Camden, whereby employers with specific requirements are linked up with autistic people with specific skill-sets. People liked the idea of focusing on the special interests to autistic adults.

Transitions

- People would like to see:
 - A mentoring system with autistic adults supporting young people with autism to transition into adulthood
 - Sharing options with parents giving a range of alternatives – It was felt that current choice for provision is limited e.g. Tower Hamlets College being only option for education

3.3 Structure of the strategy

3.3.1 The “Autism Strategy for Adults” is made up of three main sections: The first section sets the scene, collectively setting out the needs of autistic adults, how we currently meet those needs, and the national policy context. The second section sets out our aims and objectives around supporting autistic adults over the next five years. The third and final section provides more detail on how the strategy in terms of how it will be carried out, how it was developed and how it links to other strategies.

3.3.2 Throughout the strategy, attempts have been made to produce information in “plain language” that is easy to understand and scrutinise. This has been done so that the strategy can be co-owned by autistic adults and their carers.

3.4 Next Steps

3.4.1 Once approved, a Communications Plan will be drawn up to set out how the “Autism Strategy for Adults” will be communicated to staff, stakeholders, residents, service users and carers. This is with a view to ensuring that

people who have an interest in autism are aware of and engaged with the strategy over the next five years

- 3.4.2 We will set up an 'Autistic Adults Partnership Board'. This group can be made up of staff, people with autism and their carers. The group can make sure that this strategy is put into place. The group will meet regularly from summer 2017 onwards, and can develop a work plan to set out what specific actions will be worked on each year.

4. COMMENTS OF THE CHIEF FINANCE OFFICER

- 4.1 The Autism Strategy has been developed and will be delivered jointly by the Council and the Tower Hamlets Clinical Commissioning Group (CCG). The Council will deliver the relevant elements of the strategy via its operational teams. In 2017-18 and 2018-19 the Council has budgeted £330k per annum to cover the Autism Diagnostic and Intervention Service, which is funded from the Better Care Fund (BCF).

On the 4 July 2017 the 2017-18 BCF guidance was issued. The next step is to formally agree the 2017-19 BCF allocations with Tower Hamlets CCG. Should the funding of this strategy not be agreed as part of this process alternative funding arrangements will need to be identified. Further guidance is required on BCF and other potential changes to funding mechanisms for the period 2020-2022.

5. LEGAL COMMENTS

- 5.1. The Care Act 2014 places a strong emphasis on preventing and delaying needs for care and support, making sure that there is appropriate information and advice for people, support for carers, and promoting integration between social care and health care services. It also places a duty on local authorities to promote a person's well-being when carrying out any of their care and support functions in respect of that person.
- 5.2. The Council must also have regard to the Statutory Guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy dated March 2015 ("the Guidance"), which is issued by the Secretary of State pursuant to section 2 of the Autism Act 2009 and supports the Government's 2014 strategy "Think Autism". This Guidance is issued under s7 of the Local Government Social Services Act 1970, so must be followed unless there is good reason.
- 5.3. The requirements set out in the Guidance in respect of improving training around autism is consistent with the Care and Support (Assessment) Regulations 2014, which require local authorities to ensure that a person undertaking an assessment of an adult's care and support needs has suitable skills, knowledge and competence in the assessment they are undertaking, and is appropriately trained.

- 5.4. The Guidance also addresses the Council's further duties towards those on the autistic spectrum under the Care Act 2014 in respect of planning for transition from children's to adults' services and the requirements under the Children and Families Act 2014 in respect of assessments of the Education, Health and Care needs of young people up to the age of 25, and providing them with a plan which meets their needs.
- 5.5. When preparing the Council's Autism Strategy, regard must be given to the public sector equalities duty to eliminate unlawful conduct under the Equality Act 2010. The duty is set out at Section 149 of the 2010 Act. It requires the Council, when exercising its functions, to have 'due regard' to the need to eliminate discrimination (both direct and indirect discrimination), harassment and victimization and other conduct prohibited under the Act, and to advance equality of opportunity and foster good relations between those who share a 'protected characteristic' and those who do not share that protected characteristic.

6. ONE TOWER HAMLETS CONSIDERATIONS

- 6.1 The strategy notes that difficulties with social interaction and communication are some of the main characteristics of autism, which along with social stigma, can lead to social isolation for autistic adults. The strategy therefore includes an objective around social inclusion: "Help autistic people to feel like part of their community". This and the actions listed to achieve this objective are intended to promote social inclusion for autistic adults.

7. BEST VALUE (BV) IMPLICATIONS

- 7.1 The strategy has financial implications for the local authority and Clinical Commissioning Group. These implications are centred around a proposal to remodel the Autism Diagnosis and Intervention Service in Tower Hamlets so that it offers interventions to adults who have a pre-existing autism diagnosis (not just newly-diagnosed autistic adults), and a proposal to commission autism awareness training to staff working in organisations across the borough. Best value is being proposed in the following ways in relation to this:
- Remodelling the Autism Diagnosis and Intervention Service: The proposal to extend the service so that interventions can be provided to adults who have a pre-existing autism diagnosis is intended to ensure that autistic adults are provided with effective support that is focused on early intervention and crisis prevention. This, in turn, is intended to ensure that services avoid higher costs associated with crisis situations.
 - Commissioning autism awareness training: In order to secure best value, it is proposed that Tower Hamlets seek to jointly commission autism training for staff. This training could be funded regionally – for example, by the seven boroughs that make up the Sustainability and Transformation area

or the three boroughs that make up the Transforming Services Partnership.

8. SUSTAINABLE ACTION FOR A GREENER ENVIRONMENT

8.1 Not Applicable

9. RISK MANAGEMENT IMPLICATIONS

9.1 Having an effective Autism Strategy will help mitigate any risks around the needs of autistic adults not being met. This particularly includes people where Autism is their primary care need and is likely to not be assessed as having eligible social care needs if not associated with other care needs such as a learning disability.

10. CRIME AND DISORDER REDUCTION IMPLICATIONS

10.1 The strategy notes that a disproportionately high number of offenders and victims of crime have autism. The strategy therefore includes an objective around the criminal justice system: "Reduce and improve autistic people's interaction with the criminal justice system". This and the actions listed to achieve this objective are intended to reduce crime and disorder overall.

11. SAFEGUARDING IMPLICATIONS

11.1 The strategy has a number of positive implications for safeguarding vulnerable autistic adults: For example, objectives and actions aimed at improving access to health and social care service should result in more safeguarding issues being prevented or tackled at an early stage.

Linked Reports, Appendices and Background Documents

Linked Report

- NONE

Appendices

- Appendix 1: The 2017-22 Autism Strategy for Adults

Background Documents – Local Authorities (Executive Arrangements)(Access to Information)(England) Regulations 2012

- NONE.

Officer contact details for documents:

N/A