

HEALTH AND WELLBEING BOARD

10 DECEMBER 2013

Title:	Autism Self Assessment Framework and Autism Mapping Project		
Report of the Corporate Director of Adult and Community Services			
Open Report	For Decision		
Wards Affected: ALL	Key Decision: NO		
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Sponsor: Anne Bristow, Corporate Director, Adult and Community Services			
Summary: This report provides: <ul style="list-style-type: none">• An overview of the areas for improvement identified in the Autism Self Assessment Framework which assesses compliance and progress against the National Autism Strategy: <i>Fulfilling and Rewarding Lives</i>;• Key findings from the recently completed independent Autism Mapping project.			
Recommendation(s) The Health and Wellbeing Board is recommended to: <ul style="list-style-type: none">(i) Agree and validate the submitted Autism Self Assessment Framework ratings and ask the Learning Disability Partnership Board to report back on an action plan for the improvement(ii) Note the findings from the recently completed independent Autism Mapping exercise.(iii) Note the Clinical Commissioning Group and local authority will be working together through the Learning Disability Partnership Board to develop an integrated Health and Social Care Autism Strategy which will be reported back to the Board in 2014.			
Reason(s) Since the release of the National Autism Strategy in 2009, every Council with Adult Social Services Responsibilities has been required to complete an annual Autism Self Assessment Framework (SAF) to demonstrate progress towards meeting the objectives outlined in the national strategy. The Minister for Care and Support wrote to each Local Authority area in August requesting that the SAF is taken to their Health and Wellbeing Board for validation and approval. Both the National Autism Strategy: <i>Fulfilling and Rewarding Lives: the Strategy for Adults with Autism</i> and the Council's Autism Action Plan is due to be refreshed at the end of			

1. Background and Introduction

- 1.1 Autism, or Autism Spectrum Disorder (ASD) is not one condition but a spectrum of disorders within which there are common traits but wide variations in levels of functioning, with some people able to lead relatively independent lives and others requiring life-long support.
- 1.2 The National Autism Society defines Autism as, “A lifelong developmental disability that affects how a person communicates with, and relates to, other people and the world around them. It is a spectrum condition, which means that, while all people with autism share certain areas of difficulty, their condition will affect them in different ways. Asperger syndrome is a form of autism¹.”
- 1.3 People with autism, including those with Asperger syndrome, share a difficulty in making sense of the world around them. A person with autism will have three main areas of difficulty which is sometimes called the ‘triad of impairments’. They are:
 - (1) Difficulty with social communication;
 - (2) Difficulty with social interaction;
 - (3) Difficulty with social imagination.
- 1.4 In 2010 the government implemented the Autism Act and published ‘*Fulfilling and rewarding lives: the strategy for adults with autism*’, developed under the last government and which has been retained as the national strategy by the current coalition government.
- 1.5 The strategy resulted from the Autism Act, which set out governmental commitment to inclusion and full participation by adults with autism in society. A key plank of the legislation was to give people with autism who did not have a learning disability the right to an assessment for adult social care services. There was evidence that those people were being excluded from services and that it was difficult for them to get the right help, treatment and support.
- 1.6 The strategy sets out a vision for adults with autistic spectrum disorders which aspires to ensure that ‘all adults with autism are able to lead fulfilling and rewarding lives within a society that accepts and understands them. It sets out a number of rights and entitlements, which people with Autistic Spectrum Disorder should have and sets its priorities which are to achieve:
 - Increasing understanding and awareness of autism;
 - A clear consistent pathway to diagnosis;
 - Improving access for adults to services and support that they need to live independently;
 - Helping adults with autism into work;
 - Enabling local partners (social care, mental health, health, voluntary groups and mainstream services) to develop relevant services for adults with autism.

¹ <http://www.autism.org.uk/about-autism/autism-and-asperger-syndrome-an-introduction.aspx>

- 1.7 Additional funding was not made available for the implementation of '*Fulfilling and Rewarding Lives*' and the focus was on adapting and making existing services more accessible and responsive, and reallocating existing resources and funding bids in areas such as employment and social support.
- 1.8 In response to this strategy Barking and Dagenham Council put in place a multi-agency implementation plan. The Self Assessment Framework measures how we are progressing in terms of delivering against the strategy's key priorities.

2. Estimated Prevalence of People with Autism in Barking and Dagenham

- 2.1 There is consistent evidence from epidemiological surveys in the UK and the rest of the world that the prevalence of autistic spectrum disorder is somewhere between 60 and 100 people per 10,000 of the general population. The most recent British surveys suggest that prevalence is at the higher end of this estimate.
- 2.2 Prior to the introduction of a specialist diagnostic pathway led by NHS North East London Foundation Trust, assessments for adults who presented was undertaken by clinicians in the Community Learning Disability team. This had identified limited numbers who met the diagnostic criteria. In the longer term, with improved identification of children in the borough with the condition, together with the development of greater expertise amongst clinicians in identification, numbers are expected to rise.
- 2.3 Research indicates that there is a higher prevalence amongst males than females, but this gap is narrowing. From early estimates based on national prevalence and applying these rates to our local population, there could be predicted to be approximately 1,300 men and 140 women² with autism in Barking and Dagenham (1.8% of adult men, 0.2% of women)³.
- 2.4 Local authorities were asked to undertake a mapping exercise in 2012/13 in order to form a view about the numbers and needs of people in the area, and gaps in services. For most authorities this was a largely desktop exercise. In Barking & Dagenham an independent review was commissioned that involved a number of focus groups with families and people with autism themselves to hear local views about where change was required, as well as providing information about current and future need. The results of the exercise were used to supply evidence for the SAF and more detail is provided elsewhere in the report.
- 2.5 While the JSNA does not currently capture the numbers of children with autism, using the national prevalence range of 60-100 people with autistic spectrum disorder per 10,000 population in Barking and Dagenham there could be between 351 and 583 children and young people aged nineteen or under with ASD.

3. The Self-Assessment Framework and the Autism Mapping Project

- 3.1 This is the third Autism Self Assessment Framework completed by the borough and focussed on the Autism strategies priorities. There was a requirement in the

² Brugha, T. et al (2009). Autism spectrum disorders in adults living in households throughout England - Report from the Adult Psychiatric Morbidity Survey.

³ Data taken from Barking and Dagenham's Joint Strategic Needs Assessment (2012).

Self Assessment Framework to 'RAG' rate (Red, Amber or Green) progress against 37 questions set against the following domains:

- (1) Local authority area
- (2) Planning
- (3) Training
- (4) Diagnosis led by the local NHS Commissioner
- (5) Care and support
- (6) Housing & Accommodation
- (7) Employment
- (8) Criminal Justice System (CJS)
- (9) Optional Self-advocate stories
- (10) Administration questions

3.2 In this year's SAF the CCG was also required to complete a section (section 4) and the Local Authority were asked to validate it with both people with autism and the Health and Wellbeing Board. To assess progress, the Local Authority were required to either answer 'Yes' or 'No' to some questions or to RAG (red, amber or green) rate performance against a defined set criteria for each question.

Autism Mapping Project

3.3 Completion on the Autism Self-Assessment Framework follows work already undertaken as part of the Council's Autism Action Plan. A key aim of the plan, arising from the National Autism Strategy, is to "...enable local partners in developing appropriate services for adults with autism". To achieve this the Council recently completed an independent mapping project on its adult autism services which involved focus groups and interviews with professionals, stakeholders, carers and people with autism in identifying how we can improve services for people with autism.

3.4 The key findings from this project also mirrored areas in the ASAF, and have informed completion of the Framework. These included:

- Under-developed reporting of the numbers of adults with a diagnosis of autism that are receiving a service from the Council.
- An expectation as the population of the borough increases in size, together with an increase in numbers diagnosed with autism there will be an anticipated increase in demand for services.
- A need to continue to raise awareness and 'mainstream' autism in universal services so they are accessible.
- The project highlighted that the borough has a good infrastructure in place for mainstream volunteering, employment and social opportunities which should be capitalised on. There is a need to ensure that these services are adapted for adults with autism to improve accessibility.
- There are some high cost care packages for adults and children placed out of area with autism. These have been reviewed as part of the

Winterbourne View reviews and will link into the Joint Local Strategic Plan that is due to be presented to the Board in February 2014.

- Underdeveloped service planning for people with a diagnosis of autism who do not meet the clinical or eligibility criteria for either Mental Health or Learning Disability services.
- Better and improved access for adults with autism to access the mental health system / services.

4. Areas for improvement

4.1 Through completion of the ASAF, as detailed in Appendix 1, the following areas were particularly identified as requiring improvement.

4.2 **Data on the number of people with a diagnosis of autism meeting eligibility criteria for social care** – The local authority began collecting data on adults meeting the eligibility criteria in September 2012 and our data tells us that the numbers on the adult case management system (AIS) is lower than would be expected based on the national prevalence figures. We will improve the data on the number of adults with a diagnosis of autism meeting the eligibility criteria through data cleansing and through the annual review process where social workers will update the system.

4.3 **Planning for the particular needs of older people with autism.** The Council recently reviewed its older people services and identified there is a gap in identifying the needs of older people with autism in the borough. As part of our Autism Action Plan in 2014 best practice on planning and delivering services for older people with autism will be researched to learn lessons from elsewhere and see whether these can be usefully applied locally.

4.4 **Specific training for staff to carry out statutory assessments on how to make reasonable adjustments** in their approach and communicate to people with autism. Statutory assessments are completed by a registered and qualified social worker who has the relevant skills and competence to make adjustments in their approach to people with a range of communication difficulties including autism. The local authority is in the process of commissioning specific autism training for relevant staff.

4.5 In addition to the 'red' areas, the following were assessed as 'amber' and identified as areas for improvement. These are:

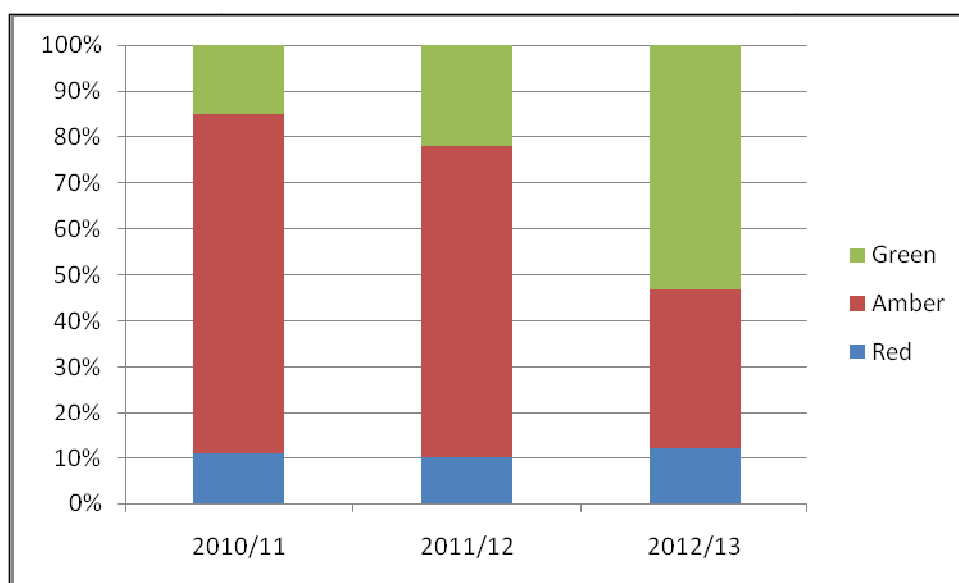
- To improve the reasonable adjustments we make to every day services;
- Autism awareness training. In addition to its e-learning package the borough is in the process of organising autism awareness training (advanced and intermediate) and NHS North East London Foundation Trust will be providing training on the diagnostic pathway. This will be targeted towards the local social care workforce as well as staff in the community and mainstream provision;
- Ensuring information about local support is accessible to people with autism;
- The consideration of the housing needs of people with autism in the Council's Housing Strategy. A commitment has been made by the Housing

Department to include a specific focus on autism when the strategy is refreshed;

- Improve the promotion to local employers around employing people with autism;
- Clinical Commissioning Group engagement- The Barking and Dagenham Autism Action Plan is due to be refreshed in 2014. This will be developed jointly by all key partners including commissioners of health services. The Local Authority will continue to work closely with the Clinical Commissioning Group to increase awareness and understanding of the needs of people with autism. Key members of the CCG are core members of the Learning Disability Partnership Board, which is the currently responsible for overseeing and implementing our Autism plan, and recently commissioned NHS NELFT to implement the ASD diagnostic pathway.

5. Progress against the Autism Action Plan

5.1 The borough continues to make progress in delivering the priorities set out in the local autism action plan.



5.2 Progress was widely attributed to the Council's detailed oversight of autism services in the borough through the mapping project together with the development in 2013 of a clear, consistent diagnostic pathway led by NHS NELFT. In addition, there has been increased awareness amongst frontline professionals with the introduction of a comprehensive autism e-learning package.

6. Consultation

6.1 In completing this year's ASAF the Council consulted people with autism on its submission to see whether they agreed with the ratings given. The ASAF has also been presented at the Learning Disability Partnership Board, and its forums (service user, carer and provider), for discussion. Additionally, as part of the ASAF four self advocacy stories from people with autism were included.

7. Mandatory Implications

Joint Strategic Needs Assessment

- 7.1 The JSNA draws on data from many sources, including national statistics and surveys. Local data is also available from many services, but in some cases this is very limited because of national data confidentiality regulations. In the case of autism, local data is in short supply, and estimating local numbers of people affected by drawing on national estimates may be unhelpful because of the small numbers involved. Section Three of the JSNA shows numbers of children with autistic spectrum disorder referred to the portage service, and these are very small. Likewise, the numbers of Barking & Dagenham pupils with statements or At School Action Plans in the borough are also fairly small, though not out of line with national prevalence estimates

Health and Wellbeing Strategy

- 7.2 In order to have good mental and physical wellbeing, all of us need a reasonable income, employment where we have some feeling of control over our work, a feeling of safety and not being discriminated against, and decent housing. This applies equally to people with autism, who may need extra support in terms of housing, employment, education and social support so that they can live independently within the community. They will also need access to sensitive helpful and actively preventive primary health care.
- 7.3 In delivering these our Health and Wellbeing Strategy Priority Area's on Care and Support is to provide children with the best start in life applies to children with autistic spectrum disorder, and sets the following goals:
- (i). 'More children identified with special needs should have their needs met and demonstrate improved health and mental health outcomes'
 - (ii). 'More children with chronic and/or complex health and social care needs are supported in an integrated way at home... And supported to continue their education'
 - (iii). 'More children with special education needs have their needs met and demonstrate improved educational and health outcomes'

In addition to Children and Young People, other priority areas in the strategy which are relevant to adults with autism include:

- (iv). 'by affirming the need to take account of the needs of the most vulnerable and excluded groups'.
 - (v). 'to promote choice, control and independence'.
 - (vi). 'supporting people to make lifestyle choices... Which will positively improve the quality and length of their lives...'
 - (vii). '...being able to take part in the design and delivery of services that are suitable for their needs.'
- 7.4 Public Health is represented on the Learning Disability Partnership Board and have contributed population and other data. Public Health have in turn gained knowledge from the Board especially about unmet needs and priorities expressed

by people with autism and learning disabilities, which have in turn been used to plan to make the JSNA more helpful and informative.

- 7.5 These critical factors are also outlined in our 'Autism Mapping Project' and will be taken into account when refreshing our autism action plan in 2014.

Integration

- 7.6 Integration between Health and Social Care is a key component in delivering the actions set out in the National Autism Strategy and progress has been made in this process through the introduction of NHS North East London Foundation Trusts Autistic Spectrum Disorder Diagnostic Pathway. Additionally, as part of the training and raising awareness of autism the borough, NELFT are planning to deliver autism awareness training for clinicians and practitioners on the new diagnostic pathway. Members of the CCG are core members of the Learning Disability Partnership Board, which is responsible for delivering the local autism plan, and have recently commissioned NHS NELFT to implement a local ASD diagnostic pathway
- 7.7 There are opportunities to joint planning and delivery of support for people with autism in an integrated way in the future. The plan is due to be refreshed in 2014, this presents an excellent opportunity for the Council and CCG to work on a joint approach to autism locally.

Financial Implications

- 7.8 As stated in the main body of the report, specific funding was not made available for the implementation of 'Fulfilling Lives' and the focus therefore is around adapting and making accessible what already exists, and reallocating existing resources and funding bids in areas such as employment and social support. However, £10k has been set aside in this year's training budget to deliver autism training to relevant staff in the coming months; quotes are currently being received to enable a training provider to be selected.

Legal Implications

- 7.9 There are no legal implications arising from this report.
- (Implications completed by Michael Henson-Webb, Solicitor, Adult Social Services)

Risk Management

- 7.10 A recent analysis of data from SEN, the Children's with Disabilities Team and numbers gathered from the local special school Trinity shows large numbers of diagnosed, known children with autism (323) who are now coming through the system which will create a demand pressure for the borough, particularly in five years time. From 2018 between 15 and 30 young people with autism are anticipated to be coming through transition from children to adult services each year.
- 7.11 If we are to engage operationally with key stakeholders in the Criminal Justice System we must also be mindful that National Offender Management Service is undergoing major reform and change which could impact this work.

8. Non-mandatory Implications

Crime and Disorder

- 8.1 As part of the Self Assessment Framework we were asked whether the Criminal Justice System were engaging in planning for adults with autism. We rated ourselves 'green' due to the boroughs excellent relationships with its CJS partners in the Community Safety Partnership, Safeguarding Adults Board and our Learning Disability Partnership Board. The borough will continue to work closely with its CJS partners around autism and they have been invited to attend the planned autism awareness training.

Safeguarding

- 8.2 Like all adults at risk people with autism are more vulnerable to criminal acts against them due to their social difficulties and may be taken advantage or become unwitting accomplices to criminal activity. The Council will continue to work closely with colleagues in safeguarding children and adults and will ensure input from these teams in the refresh of the local autism action plan in 2014.

Customer Impact

- 8.3 The SAF and Autism Mapping Project has given a clear idea on the gaps in provision and the needs of adults diagnosed with Autism in the borough. The outcomes from both pieces of work will be used as part of the Autism Action Plan refresh in 2014 which, once completed, will have a positive impact on the lives people with Autism in the borough.

Staffing issues

- 8.4 The need for specific training for staff has been identified elsewhere in the report and is now being delivered. We are exploring jointly with Havering whether it would be helpful to consider a specialist post or a low level preventative service.

9. List of Appendices:

Appendix 1: 2012 /13 Barking and Dagenham Autism Self Assessment Framework

Appendix 2: Autism Mapping Project Executive Summary