

Committee/Meeting: Cabinet	Date: 5 June 2013	Classification: Unrestricted	Report No: CAB 002/134
Report of: Anne Canning, Corporate Director, Education, Social Care and Wellbeing		Title: Adult Autism Services – Commissioning an Adults Autism Diagnostic and Intervention Service	
Originating officer: Deborah Cohen, Service Head of Commissioning and Strategy		Wards Affected: All	
Lead Member		Councillor Abdul Asad	
Community Plan Theme		A health and supportive community	

1. **SUMMARY**

- 1.1 The first national autism strategy ‘Fulfilling and Rewarding Lives’ was published in March 2010 following landmark legislation in the form of the Autism Act in 2009¹. This ensured the Government’s commitment to transforming the way in which autism was addressed in England.
- 1.2 In Tower Hamlets a multi-disciplinary Project Team (across education and social care with NHS partners and carers of people with autism) was established to drive forward delivery of services for adults with autism in line with the Act (2009), the National Autism Strategy (2010) and subsequent statutory guidance also published in 2010.

This report sets out a summary of work undertaken to date and seeks approval to commission an Adult Autism Diagnostic and Intervention Service within the Borough. This would be a new service that fills a gap in provision. This is a key component in the work:

Increase awareness and understanding of autism; Develop a clear and consistent pathway for diagnosis;

Improve access to the services and support people need to live independently within the community;

2. **DECISIONS REQUIRED**

- 2.1 The Mayor in Cabinet is recommended to approve the following proposals to:
- (i) Establish a new Adults Diagnostic and Intervention Service (Appendix 1); in partnership with Tower Hamlets Clinical Commissioning Group using NHS section 256 funding, commissioned via NHS procurement procedures and

¹ <http://www.autism.org.uk/Working-with/Autism-strategy.aspx>

- (ii) Commission this service through the Council with advice from clinical commissioners within the NHS.

3. REASONS FOR THE DECISIONS

3.1 The proposed changes support:

- (1) Meeting statutory obligations of the National Autism Act 2009;
- (2) Delivering reforms set out in the Children's and Families Bill 2013²; and
- (3) Having services in place to meet the needs of residents who meet eligibility criteria (Fair Access to Care Services³).

4. ALTERNATIVE OPTIONS

4.1 People who have a learning disability as their primary identified need, as well as Autism, are usually seen by the Community Learning Disability Services but it is unlikely that they will have access to the specialist service they need. There is currently a lack of capacity within the Community Learning Disability Service (CLDS) or local mental health services, to take on of the additional role of delivering a clear and consistent pathway for autism diagnosis through the offer of a diagnostic and post-diagnostic support service. People who are high functioning, including those with Asperger's Syndrome who often have an average or above average IQ, are often undiagnosed until a time of crisis, which may be a mental health breakdown or their carer not being able to cope. Access to a range of support, including "talking therapies", behavioural support can greatly increase goals and aspirations for individuals and their families and carers. Consultation with local carers at drop-in sessions and learning from visits to national best practice (the Liverpool Asperger Service) also shows that people with autism (a social communication disorder) identify better with specialist autism services and not those associated with having a learning disability or mental health condition. For this reason, a reconfiguration or expansion of the Community Learning Disabilities Service is not recommended as viable at this time.

4.2 Due to the legislative requirement to have these services not implementing the proposed option presents the following risks:

A large undiagnosed population of young people in transition and adults with autism not able to access and receive services appropriate to need. Due to the lack of services for adults, once young people with autism leave school they can become dislocated from support services, isolated and not able to access social and economic opportunities that can lead to fulfilling and rewarding lives; Tower Hamlets not meeting its obligations under the National Autism Act 2009 (particularly in relation to developing a clear and consistent path for diagnosis);

² www.education.gov.uk/a00221161/children-families-bill

³ www.towerhamlets.gov.uk/lgs/251-300/287_who_can_get_support.aspx

Tower Hamlets rated as red for delivery against aims of the national autism strategy (monitored up to now through the Public Health Observatory) and Autism Self-Assessment Framework; and Carers of people with autism not accessing appropriate community based support with the potential for their condition to escalate into requiring more costly high need support. The Royal College of General Practitioners report that 40% of carers will experience depression or mental health problems.⁴

5. BACKGROUND

- 5.1 Autistic Spectrum Disorder (ASD) is a lifelong developmental disorder characterised by impairments in social interaction, social imagination and communication. Although some people may live relatively independently, others will have high dependency needs requiring a lifetime of specialist care.
- 5.2 The spectrum includes autism and Asperger's syndrome. People with ASD may have a range of very different needs; some people may be non-verbal or have a severe learning disability, whilst those with Asperger's syndrome often have an average or above average IQ.
- 5.3 Characteristics of ASD include:
 - Difficulty with social relationships
 - Difficulty with understanding others' intentions or viewpoints
 - Difficulty with both verbal and non-verbal communication
 - Difficulty with interpersonal play and imagination
 - Difficulty in understanding sub-texts and abstract meanings
 - Repetitive patterns of behaviour
 - Resistance to change in routine
 - Hypersensitivity to stimuli (e.g. sound, touch, pain, light, etc.)
- 5.4 ASD is often under-diagnosed, under-reported and misdiagnosed, largely due to the social and communication difficulties listed above.

Autism Act 2009

- 5.5 The Autism Act received Royal Assent in November 2009; it was the first legislation to focus on a particular disorder and ensured that the Government made a commitment to improving service provision and support for those with autism.
- 5.6 Statutory guidance published in 2010 covered: training of staff, identification and diagnosis of autism in adults, planning in relation to the provision of services to the people with autism and local planning and leadership in relation to the provision of services for adults with autism.
- 5.7 The guidance notes that although it provides direction, the ultimate aim is that

⁴ <http://www.guardian.co.uk/society/2013/may/11/carers-monitored-mental-health-problems>

local areas apply it to reflect local needs, existing strengths in service provision and the landscape they work in.

- 5.8 As the guidance is **statutory**, local councils and local health bodies have a legal duty to implement it. Where the guidance says that a local area **should** do something, this means that they will have to do it by law, unless they have a strong reason not to. Lack of money will not necessarily be a strong reason. If they do not follow guidance they can be challenged through the courts.
- 5.9 The 2009 Act did not come with any additional funding for the Council and local NHS to implement.
- 5.10 Progress nationally to deliver against obligations of the 2009 Act has been slow due to its staged introduction, via statutory guidance in 2010, and introduction of a national Self-Assessment Framework in 2011 at a time of severe pressure on resources in the public sector.
- 5.11 In April 2011 NHS London carried out an exercise to map progress on delivery against the 2009 Autism Act. This was delivered through the introduction of a new Autism Self-Assessment Framework with findings published in March 2012⁵.

LBTH participated in the Self-Assessment Framework return. This showed work was required locally to meet obligations of the 2009 Autism Act, particularly to put in place a clear pathway to diagnose and assess adults with autism reflecting recent 'National Institute for Health and Clinical Excellence' (NICE) guidelines for recognition, referral, diagnosis and management of adults on the autism spectrum⁶. This would include where appropriate working with young people leaving school and moving into adult life (moving through "transition").

Children and Families Bill 2013

- 5.12 The Children's and Families Bill was published by the Department for Education on Tuesday, 5 February 2013 and is at Committee stage in the House of Commons⁷.
- 5.13 The main elements of the Bill to consider locally for children with special educational needs and disabilities are:

Replacing Special Educational Needs (SEN) statements and Learning Disability Assessments (for 16-25 year olds) with a single, simpler 0-25 assessment process and Education, Health and Care Plan from 2014;
Providing statutory protections comparable to those currently associated with a statement of SEN to up to age 25 in further education - instead of being cut off at age 16;
Requiring that local authorities and health services jointly plan and commission services that children, young people and their families

⁵Public Health England: www.improvinghealthandlives.org.uk/news.php?nid=1892

⁶ Clinical guidelines, CG142 - Issued: June 2012: <http://www.nice.org.uk/CG142>

⁷Parliament Children and Families Bill: <http://services.parliament.uk/bills/2012-13/childrenandfamilies.html>

need; and
Giving parents or young people the right to a personal budget for their support.

Local Planning

- 5.14 It is estimated that there are 1990 adults aged 18+ with ASD in Tower Hamlets and 765 adults with ASD and no additional learning disability. There are 296 young people aged 3 to 18 in local schools with an autism diagnosis as their most prevalent condition. The Joint Strategic Needs Analysis Factsheet⁸ attached at Appendix 1 sets out a more detailed breakdown of local population data.
- 5.15 There is an Autism Assessment Service for children and a wide range of support services in place, from special schools and Special Education Need Co-ordinators, through to a commissioned National Autistic Society family support service. There is no specialist adult autism assessment service in the Borough.
- 5.16 Due to this gap in service, once young people with autism leave school they can become dislocated from support services, isolated and not able to access social and economic opportunities that can lead to fulfilling and rewarding lives. The Educational Psychology Service maintains data on young people with autism to support service planning and commissioning intentions. Public Health has also published a factsheet on Autism Spectrum Disorder which is attached as Appendix 2.
- 5.17 Not taking into account the current adult population with autism; in the next 10 years a minimum of 130 young people with a Statement of Educational Need (SEN) listing autism as their most prevalent condition⁹ will move from children to adult services and require some level of support and guidance. This may be a conservative estimate given that it only counts young people with statements and omits those with special needs below the statementing threshold.
- 5.18 A recent review of autism services in LB Southwark showed that there were a similar number of pupils with autism reported through school CENSUS data to those who were identified through having a statement of need with autism as the primary condition. This would confirm the accuracy of the using numbers of stated children as the basis for planning services.
- 5.19 Linking in with a planned adult autism diagnostic and post diagnostic support services and using this information to actively plan the journey from children's into adult services will be a key mechanism to identify, offer a diagnosis and support people with ASD in future.

⁸Tower Hamlets JSNA Autism Factsheet: http://www.towerhamlets.gov.uk/lgs/701-750/732_jsna.aspx

⁹ Data as per LBTH Impulse database @ 15/01/13

6. PROPOSAL TO DEVELOP SERVICES: Local Diagnostic and Intervention Services

- 6.1 An LBTH Autism Project Team was established in 2011 to oversee the development of local adult autism services. The Project Team is chaired by the Service Head for Adult Social Care and has membership from education, Public Health, NHS, Phoenix School, carer and social care commissioning representatives.
- 6.2 In addition to the Project Team, work is informed by a 'Clinical & Practitioner Reference Group' established within the Community Learning Disability Service. This group has membership across social work, speech and language therapy, psychology and psychiatry and includes staff from the transition service. The group is specifically tasked with developing a clear and consistent pathway for diagnosis and ensuring that health and social care staff make reasonable adjustments to services to meet the needs of adults with autism.
- 6.3 The Project Team has been pro-active in putting in place a number of initiatives to ensure LBTH delivers against obligations of the Autism Act 2009 and Children's and Family Bill 2013 reforms. These include:

Training 150 front-line adult social care staff in autism awareness during 2012/13 with eight more training sessions planned for 2013/14;
Working closely with the Phoenix School to review training and employment opportunities for young people with autism leaving school;
Specialist autism support within the local Jobs, Enterprise and Training service to improve access to education and work;
Set up of a local Autism Drop-in for carers and people with autism which offers the opportunity to disseminate information and advice whilst facilitating peer to peer support. The drop-in is closely linked with the Phoenix School and Special Educational Needs outreach team to offer support to carers who have children moving from children to adult services ensuring a continuum of support;
Establishing a local Autism Partnership Board;
Developing an outcome monitoring tool to assess change in wellbeing and quality of life for adults with autism accessing new services; and
Wide ranging consultation to inform local planning via workshops in each paired Local Area Partnership Area and web based consultation and questionnaire available in main community languages¹⁰.

- 6.4 The Council has worked with the National Autistic Society to develop the plans presented in this paper.
- 6.5 A key element in local planning is to set-up a **local Adult Autism Diagnostic and Intervention Service**. This will be done through a three year partnership with the Tower Hamlets NHS Clinical Commissioning Group. The Council will

¹⁰Tower Hamlets Autism Consultation:
www.towerhamlets.gov.uk/lgs/851-900/867_consultation/autism_consultation.aspx

lead on the procurement of this service. The service will cost up to £333k per annum, £1m over the proposed three year period, and will be funded from NHS Section 256 monies that have been agreed with the NHS. Because the future of this funding is not confirmed beyond 2015/16 it is proposed over the first two years of the new service, to carry out a review of the existing Community Learning Disability Services, which are part Council, part NHS funded, to identify the extent to which either the Autism service can be moved into the wider LD Service (as is the case in some boroughs) or to reallocate resources, working with the NHS

The Council (including Public Health) and NHS colleagues have worked in partnership to agree a service delivery plan to support some of the most vulnerable people living in the Borough. The service specification and method statement will be drafted by LBTH with input from NHS professionals and clinicians and will ensure that London Living Wage, local employment and other community benefits apply. Service outcomes and outputs will be monitored through the local Autism Partnership Board which is chaired by the Council's Service Head of Adult Social Care. The contract will have an annual break clause in it and will be subject to close monitoring, including a full review 6 months into the contract, as is appropriate to a brand new service to ensure that activity levels and outcomes are meeting expectations.

7. COMMENTS OF THE CHIEF FINANCIAL OFFICER

- 7.1 The report seeks approval to create a three year partnership with Tower Hamlets Clinical Commissioning Group for the provision of a new Diagnostic and Intervention Service for clients that have autism. This will allow the Council to meet some of its obligations under the Autism Act 2009.
- 7.2 The cost of this three year contract is £1m and will be met from existing resources negotiated with the NHS under a section 256 agreement.
- 7.3 Work to identify funding to continue a service beyond the three years of the contract will be initiated in year 1 of the contract.

8. CONCURRENT REPORT OF THE ASSISTANT CHIEF EXECUTIVE (LEGAL SERVICES)

- 8.1 Section 2 of the Autism Act 2009 ("the 2009 Act") required the Secretary of State to issue guidance to local authorities about the exercise of their social services functions (within the meaning of the Local Authority Social Services Act 1970). The Council is required to carry out its social services functions under the statutory guidance. This means that the Council should act in accordance with the statutory guidance and only depart from it where the authority considers that there is good reason to do so, for example because the authority can show that it is providing an equivalent or better alternative
- 8.2 The statutory guidance which is entitled Implementing "Fulfilling and rewarding lives, Statutory guidance for local authorities and NHS Bodies to

support implementation of the autism strategy” was issued in December 2010. The guidance reminds authorities of the relevant policies, and their existing duties and responsibilities, and sets out additional guidance to help authorities to implement the strategy.

8.3 The Children & Families Bill referred to in the report is not yet law. The Committee stage of the Bill was completed on 25 April 2013 and the report stage and third reading will take place on a date to be announced. As drafted, the Bill contains the following reforms –

- Transforming the system for young people with special educational needs (“SEN”) including those who are disabled.
- Extending the SEN system from birth to age 25.
- Replacing the current system of assessment and statements of SEN with assessments of the education, health care and social care (“EHC”) needs of young persons and EHC plans.
- A number of provisions which are aimed at improving co-operation between all the services that support children and their families, and in particular requires that local authorities and health authorities work together for this purpose.

8.4 Section 3 of the Local Government Act 1999 requires best value authorities, including the Council, to “make arrangements to secure continuous improvement in the way in which its functions are exercised, having regard to a combination of economy, efficiency and effectiveness”.

8.5 The Public Services (Social Values) Act 2013 came into force on 31st January 2013. This requires the Council to consider how the services it commissions and procures might improve the economic, social and environmental wellbeing of the area.

8.6 The contracts for this type of service are Part B Services and so the full provisions of the Public Contract Regulations 2006 do not apply. However they are still expressly subject to the equality and transparency obligations under the Regulations and there is a requirement to have a fair and transparent process. There are also requirements arising from duties under the Equalities Act. This report explains how that will be achieved.

8.7 Before transforming or commissioning services, the Council must have due regard to the need to eliminate unlawful conduct under the Equality Act 2010, the need to advance equality of opportunity and the need to foster good relations between persons who share a protected characteristic and those who don't. Some form of equality analysis will be required in order to ensure that due regard is given.

9. ONE TOWER HAMLETS CONSIDERATIONS

9.1 An Equalities Impact Assessment (EqIA) has been completed and is in place as part of the 9th February 2011 and 8th February 2012 Cabinet reports on

Modernising Learning Disability Services. A recent update on this EqIA has been submitted as part of the Council's corporate monitoring process.

9.2 The EqIA recognised that that these proposals will affect some of the most vulnerable people living in LBTH. It was completed with input from the Adults, Health and Wellbeing Departmental Equalities Focus Group and Head of Scrutiny and Equalities. The EqIA has an action plan in place to ensure the modernisation programme does not adversely impact upon anyone with a learning disability or autism regardless of their race, disability, age, gender, socio-economic status, sexual orientation, religion or belief. The EqIA also has a number of actions in place to ensure the views of parents and carers of people with autism are taken into account and they are not adversely impacted upon as part of proposed plans.

9.3 Plans have been developed in on-going consultation with:

- Carers of People with Autism
- People with Autism
- Clinical Commissioning Group
- East London Foundation Trust
- Adults and Children's Clinician and Practitioner Teams
- Commissioning and Health Senior Management Team
- Education, Social Care and Wellbeing Departmental Management Team
- Local and current providers of autism services
- Local schools

9.4 Consultation is on-going via the following methods:

- Through membership on the Autism Project Team (and on-going Autism Partnership Board)
- Consultation via questionnaire and workshop sessions in each paired LAP (Local Area Partnership Area)
- Website page set up: www.towerhamlets.gov.uk/lgsi/851-900/867_consultation/autism_consultation.aspx
- Set up of local drop-in services (established and on-going)
- Via East End Life and other local press
- Local Provider forum
- Phoenix School will be the hub for the consultation with young people and their parents/carers

10. SUSTAINABLE ACTION FOR A GREENER ENVIRONMENT

10.1 The design, construction and running of any new facilities will follow best practice and the Council's Environmental Strategy.

11. RISK MANAGEMENT IMPLICATIONS

11.1 The key risks in taking forward these proposals to modernise autism services in Tower Hamlets are:

- (i) Section 256 funding for the Diagnostic and Intervention Service is non-recurrent. The proposed total funding in this paper totals £1m for a three year contract and at present there is no identification of recurrent funding. In the light of this it is proposed that over the first two years of the service, to carry out a review of the existing Community Learning Disability Services, which are part Council, part NHS funded, to identify the extent to which either the service can be moved into the wider LD Service (as is the case in some boroughs) or to reallocate resources from the Community Learning Disability Service;
- (ii) Being in breach of statutory obligations under Autism Act 2009 as set out in paragraph 4.2 above (particularly in relation to developing a clear and consistent path for diagnosis). This is mitigated by the proposed Diagnostic and Intervention Team; and
- (iii) The final endorsement of the plan for 13-14 s256 funding is expected in July 2013. Approval is expected as the NHS locally is a partner to these plans for the Autism Services.

12. CRIME AND DISORDER REDUCTION IMPLICATIONS

12.1 Modernisation plans will ensure that the safety and welfare of people with autism will be fully considered in the development of any new services. Partnership working with the Community Safety Team will ensure that people with autism are safe, not only in new services to be delivered, but also during any travel undertaken to attend new services.

13. EFFICIENCY STATEMENT

13.1 The model proposed will significantly increase the range and quality of services, whilst having the added benefit of meeting statutory obligations of the National Autism Act 2009.

14. APPENDICES

Appendix 1 – Diagnostic and Intervention Team

Appendix 2 – Joint Strategic Needs Analysis - Autism Factsheet

Brief description of “background papers”:

Equalities Impact Assessment (EqIA) as part of the 9th February 2011 and 8th February 2012 Cabinet reports on Modernising Learning Disability Services, including recent update on this EqIA

Barbara Disney
020 7364 20225
4th floor Mulberry Place
5 Clove Crescent
London E14.2BG