

Joint Strategic Needs Assessment 2016-2017

Executive summary

This factsheet considers Autism Spectrum Disorder (ASD) in adults only. The needs of children with ASD are considered separately as part of the Children with Disabilities JSNA factsheet. However this JSNA makes reference to Children's and Young People services when it is required to understand the needs of Adults with ASD.

There were thought to be around 2125 people aged 18-64 and 153 aged 65+ predicted to have ASD in Tower Hamlets in 2015¹, approximately 1445 (50%) of whom were estimated to not also have a learning disability². However this figure should be approached with caution as research findings on the proportion of people with ASD that also have learning disabilities (IQ less than 70) vary considerably³.

People with ASD often experience impairments in social interaction, social imagination and communication. Care pathways and service provision for children with ASD are reasonably well established in Tower Hamlets, whereas those for adults with ASD are less so.

Statutory guidance has been published to ensure local implementation of the National Adult Autism Strategy. This guidance tells local authorities and NHS bodies what actions should be taken to meet the needs of people with ASD living in their area. Tower Hamlets is not currently assessed as fully meeting the requirements of the National Adult Autism Strategy; however work is underway to develop a Local Autism Strategy to direct the implementation of the national strategy.

Recommendations

- There is little data on the uptake of the ASD training that is available to staff. This should be improved to allow audit of training.
- Workforce training data should be collected from all statutory organisations and collated annually, gaps should be identified and plans developed to address shortfalls.
- An ASD training plan should be included in the adults' Autism Strategy
- A review of the pathways for referral to the Tower Hamlets Autism and Diagnostic Service (THAS) to ensure that all stakeholders including GPs, the Community Learning Disability Service (CLDS), and Adult Social Care services are aware of the services and are confident regarding referral.
- The development of Adults' Autism and Children and Young People's Special Educational Needs and Disability (SEND) strategies should include planning for transition to ensure that continuity of care may be maintained. Further evaluation of the transition pathway may be required.
- The proposed Autism Strategy should include measures to improve the capture of relevant data to inform needs assessment and allow for the monitoring of effectiveness of services.

¹ Institute of Public Care 2016 Projecting Adult Needs and Service Information and Projecting Older People Population Information <http://www.pansi.org.uk/> & <http://www.poppi.org.uk/>

² NICE Autism January 2014 NICE quality standard 51 <https://www.nice.org.uk/guidance/qs51>

³ National Autistic Society "about autism" <http://www.autism.org.uk/>

- Tower Hamlets Housing Strategy should make reference to the specific needs of people with ASD. Local housing offices should have at least one staff member who has training in autism to facilitate the housing needs of those with ASD
- The Autism Strategy should ensure that transition planning includes a focus on the educational and employment needs of people with ASD as appropriate
- Stakeholders from the Criminal Justice Sector should be included in the development of the Autism Strategy to raise the profile of the needs of people with ASD within this sector.
- Data from the THAS and from social care assessments should be reviewed to ensure that commissioned services are meeting the needs of the population. People with ASD should be included as key stakeholders in the development of the Autism Strategy to ensure that it meets the needs of the service users

1 What is autistic spectrum disorder?

Autistic Spectrum Disorder (ASD) is a lifelong developmental disorder characterised by impairments in social interaction, social imagination and communication. The spectrum includes autism and Asperger's syndrome. The exact cause of autism spectrum disorder (ASD) is currently unknown. It's a complex condition and may occur as a result of genetic predisposition (a natural tendency), environmental or unknown factors. Possible triggers include being born prematurely (before 35 weeks of pregnancy), or being exposed in the womb to alcohol or to certain medication, such as sodium valproate (sometimes used to treat epilepsy during pregnancy).

No conclusive evidence has been found linking pollution or maternal infections in pregnancy with an increased risk of ASD.

Only approximately 50% of people with autism have an intellectual disability (IQ below 70). Around 70% of people with autism also meet diagnostic criteria for at least one other (often unrecognised) physical or mental health problem, such as sleep problems, eating problems, epilepsy, anxiety, depression, problems with attention, dyspraxia, motor coordination problems, sensory sensitivities, self-injurious behaviour and other behaviour that challenges (sometimes aggressive). These problems can substantially affect the person's quality of life, and that of their families or carers, and lead to social vulnerability⁴.

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.

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)

Adult ASD is often under-diagnosed, under-reported and misdiagnosed, largely due to the social and communication difficulties listed above. There is no specific test for ASD. A diagnosis of ASD is based on the range of features evaluated by a combination of specialists who work together to make an assessment.

⁴ NICE Autism January 2014 NICE quality standard 51 <https://www.nice.org.uk/guidance/qs51>

2 What is the policy context?

The National Institute for Health and Care Excellence (NICE) have published a pathway and standards for ASD. The NICE care pathway for Autism covers the recognition, referral, diagnosis and management of autism in children, young people and adults.

<http://pathways.nice.org.uk/pathways/autism>

NICE Autism Quality Standard, Jan 2014 (QS51) covers autism in children, young people and adults, including both health and social care services. <http://guidance.nice.org.uk/qs51>

The Autism Act (2009) requires each local authority to develop a local autism strategy for the provision of health and social care services for people with autism (aged 14 years and older).

<http://www.legislation.gov.uk/ukpga/2009/15/introduction>

The Autism Act (2009) was the first ever disability-specific law in England. The Act made two requirements with reference to adults:

- The first was to put a duty on the Government to produce a strategy for **adults** with autism, which was published in March 2010.
- The second was a duty on the Government to produce statutory guidance for local councils and local health bodies on implementing the adult autism strategy by the end of 2010. This guidance was published in December 2010.

The adult autism strategy is the Government's plan for actions to ensure adults with autism get the help that they need. The linked statutory guidance also directs local councils and health services how they can help people with autism.

The first ever strategy for adults with autism in England - entitled Fulfilling and Rewarding Lives - was published in 2010. In 2013, the Government asked for feedback about how well the 2010 strategy had been implemented so far. The new strategy - Think Autism⁵ - was published in April 2014. This sets 15 challenges to meet the needs of people with ASD.

Statutory guidance has been published to ensure the local implementation of the National Adult Autism Strategy. This guidance tells local authorities and NHS bodies what actions should be taken to meet the needs of people with autism living in their area. The Government published new statutory guidance⁶ in March 2015, which replaced an existing guidance from 2010.

Developmental work on an autism strategy has been carried out in parallel with work on this JSNA. A local Autism Strategy applicable to adults is in the process of being developed and is due in early 2017.

3. What is the local Picture?

Recent estimates suggest that there are approximately 450,000 adults nationally living with autism – 1.1% of the population. The rate of autism among men (2.0%) is higher than among women

⁵ HM Government (2014), Think Autism Fulfilling and Rewarding Lives, the strategy for adults with autism in England: (https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/299866/Autism_Strategy.pdf)

⁶ DH (2015) Statutory guidance to support implementation of the Adult Autism Strategy (https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/422338/autism-guidance.pdf)

(0.3%). The current evidence suggests that the prevalence of autism in adults who also have learning disabilities is between 7% and 20%⁷.

Projecting Adult Needs and Service Information (PANSI) and Projecting Older People Population Information System (POPPI) has estimated future prevalence rates of autism in adults, by applying ONS population projections to the 18 + age group. Table 1 below summarises the future trend in Tower Hamlets:

Table 1 Tower Hamlets Adults predicted to have ASD, by age and gender, projected to 2030

	2014	2015	2020	2025	2030
Males aged 18-24	299	297	299	304	335
Males aged 25-34	761	774	797	788	776
Males aged 35-44	436	455	551	614	630
Males aged 45-54	245	256	304	353	410
Males aged 55-64	140	148	178	211	245
Males aged 65+	83	83	98	117	144
Total adult males	1,964	2,013	2,227	2,387	2,540
Females aged 18-24	36	36	36	36	40
Females aged 25-34	79	80	82	80	78
Females aged 35-44	38	41	51	56	57
Females aged 45-54	22	23	27	33	39
Females aged 55-64	15	15	18	20	23
Females aged 65+	72	70	70	78	90
Total adult females	262	265	284	303	327
Total Adults	2,226	2,278	2,511	2,690	2,867

There are thought to be around 2125 people aged 18-64 and 153 aged 65+ predicted to have ASD in Tower Hamlets in 2015⁸, approximately 1445 (50%) of whom are estimated to not also have a learning disability⁹. However this figure should be approached with caution as research findings on the proportion of people with autism spectrum disorders that also have learning disabilities (IQ less than 70) vary considerably¹⁰.

Some very able people with ASD may never come to the attention of services as having special needs, because they have developed strategies to overcome any difficulties with communication and social interaction, and found fulfilling employment. Other people with ASD may be able intellectually, but have need of support from services, because the degree of impairment they have of social interaction hampers their chances of employment and achieving independence.

There are currently no GP registers for ASD in Tower Hamlets, which makes it difficult to establish the number of adults with a diagnosis. As such the number of adults with a diagnosis is unknown. Tower Hamlets Autism Diagnosis & Intervention Service has offered a pathway for diagnosis of ASD in adults since 2014-15. The total number of referrals (including self-referrals) for diagnosis since the start of the project to end of 2015-16 is 221¹¹.

⁷ The NHS Information Centre, Community and Mental Health Team, Brugha, T. et al (2012). Estimating the prevalence of autism spectrum conditions in adults: extending the 2007 Adult Psychiatric Morbidity Survey. Leeds: NHS Information Centre for Health and Social Care

⁸ Institute of Public Care 2016 Projecting Adult Needs and Service Information and Projecting Older People Population Information <http://www.pansi.org.uk/> & <http://www.poppi.org.uk/>

⁹ NICE Autism January 2014 NICE quality standard 51 <https://www.nice.org.uk/guidance/qs51>

¹⁰ National Autistic Society "about autism" <http://www.autism.org.uk/>

¹¹ Tower Hamlets Autism Diagnostic and Intervention Service data

We may estimate the future need for Adult ASD services by review of the prevalence of Childhood ASD. “Improving Health and Lives” is a collaboration between three organisations: Public Health England, the Centre for Disability Research at the University of Lancaster and the National Development Team for Inclusion. They have modelled data for how many schoolchildren aged 7-15 with ASD can be expected to live in each region, local authority and ward in England.

They have estimated that approximately 126 children will have ASD in Tower Hamlets¹². However this is very low in compared to the prevalence of diagnosed Autism in the area. The figures for Children and Young People with a diagnosis of ASD are shown in table 1 below. No further breakdown of this data is available.

Table 2 Children and Young People with a diagnosis of ASD¹³

Pre School			Primary			Secondary (+)		
M	F	Total	M	F	Total	M	F	Total
37	16	53	418	64	482	206	60	266

This data includes children and young people aged between 0-25 years (though currently no-one is over 20 years) who live in Tower Hamlets and are attending school (either in Tower Hamlets or outside of the borough) or are of pre-school age. In total there are 801 Children and Young People with a diagnosis of ASD. This is clearly higher than the modelled levels. National research has suggested no statistically significant difference in ASD prevalence by ethnic origin. However, diagnoses are more common in males, and maternal immigration has been associated with increased risk of ASD¹⁴.

Data available from 2007 onwards illustrates a disproportionate rise in the number of children with ASD in Tower Hamlets, from 159 children in 2007, to 270 children in 2011, and 801 in 2016¹⁵. This data indicates the number of diagnoses has increased by nearly 200% over a five year period. This compares to just an approximate 30% increase in the size of the local population over the same period of time¹⁶.

This increase in the prevalence of ASD is remarkable. It is difficult to ascertain whether this relates to real increases in incidence of ASD or improved recording of SEND data. It seems clear that the figures indicate both the effectiveness of childhood diagnostic services and the need for effective ASD support services for both children and adults in the borough. Given the high prevalence of autism in young people, and the estimated levels of autism, it seems likely that the level of undiagnosed adult autism in the borough remains very high.

4. What are the effective interventions?

The exact cause of ASD is currently unknown and there are no recommended primary prevention measures to lower the risk of developing the condition.

Secondly there are no effective medical treatments for ASD, particularly in adulthood. However, we may improve the quality of life of those with the condition by ensuring that carers and health

¹² Learning Disabilities Observatory, Local variations in how many children have learning disabilities or autism, <https://www.improvinghealthandlives.org.uk/projects/howmanyhavelearningdisabilities/numbers/index.php?LA=00BG>

¹³ Based on figures provided by the Educational Psychology Service, Phoenix Outreach Team and the Autistic Spectrum Disorder Assessment Service (ASDAS) in December 2015.

¹⁴ D. V. Keen, F. D. Reid, D. Arnone, Autism, ethnicity and maternal immigration, The British Journal of Psychiatry Apr 2010, 196 (4) 274-281; DOI: 10.1192/bjp.bp.109.065490

¹⁵ Tower Hamlets, JSNA Factsheet – Autism Spectrum Disorder 2011

¹⁶ Tower Hamlets, Research Briefing on GLA Population Projections for Tower Hamlets January 2016

and social care staff can recognise ASD and accept, understand and communicate with those who have it. Additionally we can ensure that social care services are developed which support the needs of people with ASD.

Statutory guidance has been published to ensure the local implementation of the National Adult Autism Strategy. This guidance tells local authorities and NHS bodies what actions should be taken to meet the needs of people with autism living in their area. The Government published new statutory guidance in March 2015, which replaced an existing guidance from 2010. A summary of the required actions for services is provided below:

1. Training of staff who provide services to adults with autism

The original strategy stated that it is important that autism training should be available for everyone working in health or social care. This goal has been restated in Think Autism in Priority Challenge 4 ('I want the everyday services that I come into contact with to know how to make reasonable adjustments to include me and accept me as I am. I want the staff who work in them to be aware and accepting of autism'). Training should aim to change staff behaviour and attitudes as well as improve knowledge and understanding of autism. The guidance for implementing the strategy suggests both general autism awareness training and specialised training for staff in key roles.

2. Identification and diagnosis of autism in adults, leading to assessment of needs for relevant services

For many people with autism and their families and carers, having a clear clinical diagnosis of autism is an important step towards leading fulfilling and rewarding lives. A diagnosis can help people understand their own and family members' behaviour and responses, and enable the diagnosed person to access services and support. However, the strategy emphasised that a diagnosis is not the end in itself, but should be part of an integrated process.

3. Local planning and leadership in relation to the provision of services for adults with autism

The adult autism strategy and the associated statutory guidance include a number of recommendations and expectations about the planning of services for adults with autism locally. These include:

- the appointment of a joint commissioner or senior manager with lead responsibility for services for adults with autism
- the development of a local commissioning plan for adults with autism based on the Joint Strategic Needs Assessment (JSNA) and other relevant local work
- the improvement of transition planning for young people with autism reaching school leaving age
- the improvement of transition planning and reasonable adjustments to services and support for older adults with autism reaching retirement age to enable them to live independently

4. Care and Support

Both the Strategy and the Guidance have a number of recommendations about the care and support an adult with autism should receive to live independently and access mainstream services. This includes achieving the same improvement to public services for people with autism that has occurred for people with learning disabilities and mental health problems through existing programmes. There has been feedback to suggest that people with autism are missing out due to not fitting into either of these categories. In Think Autism, Priority Challenge nine sets out what is required here: 'I want staff in health and social care services to understand that I have autism and how this affects me'. Personalisation is intended to help ensure not only that there is a recognition of people's individual needs, but also that services can be configured to meet them.

5. Housing and accommodation

The strategy aims to enable adults with autism and their families to have greater choice and control over where and how they live. This means that planning of local housing should take into account the needs of adults with autism.

6. Employment

Helping adults with autism into work was one of the key areas of the original Autism Strategy. Only 15% of autistic adults in the UK are in full-time paid employment¹⁷. The guidance emphasised employment as an aspect of effective transition planning. In Think Autism the stress laid on the importance of employment opportunities is continued. Priority Challenge 15 restates this: 'I want support to get a job and support from my employer to help me keep it'.

7. Criminal Justice System

The first Autism Strategy recommended that all staff within the criminal justice sector should have training and access to expertise to enable them to support people with autism. In addition, pathways through the system should be developed to identify others with whom they may need to work. This emphasis on the need for autism awareness in all parts of the criminal justice system is restated in Think Autism. Priority Challenge 13 states: 'If I break the law, I want the criminal justice system to think about autism and to know how to work well with other services.'

8. Transition

Local autism teams should ensure that young people with autism who are receiving treatment and care from child and adolescent mental health services (CAMHS) or child health services are reassessed at around 14 years to establish the need for continuing treatment into adulthood. Transition planning guidance is set out in NICE guidelines [CG170] on Autism¹⁸. If continuing treatment is necessary, arrangements should be made for a smooth transition to adult services and information given to the young person about the treatment and services they may need. The timing of transition may vary locally and individually but should usually be completed by the time the young person is 18 years old. Variations should be agreed by both child and adult services. As part of the preparation for the transition to adult services, health and social care professionals should carry out a comprehensive assessment of the young person with autism. The assessment should make best use of existing documentation about personal, educational, occupational, social and communication functioning, and should include assessment of any coexisting conditions. For young people aged 16 or older whose needs are complex or severe, the care programme approach (CPA) in England, or care and treatment plans in Wales, should be used as an aid to transfer between services. Planning should involve the young person and, where appropriate, their parents or carers. Information about adult services should be provided to the young person, and their parents or carers, including their right to a social care assessment at age 18. During transition to adult services, a formal meeting involving health and social care and other relevant professionals from child and adult services should be considered.

5. What is being done locally to address this issue?

The development of the adult autism strategy is being led by Tower Hamlets Council's Strategy Team. An assessment of the extent of the implementation is conducted annually via the completion of a self-assessment exercise. The results of the latest assessment (2013) are summarised below:

1. Training of staff who provide services to adults with autism

Tower Hamlets has developed multiagency training. A comprehensive range of local autism

¹⁷ Redman, S et al (2009). *Don't Write Me Off: Make the system fair for people with autism*. London: The National Autistic Society, p8

¹⁸ <https://www.nice.org.uk/guidance/cg170/chapter/1-recommendations#transition-to-adult-services-2>

training that meets NICE guidelines (Taster sessions, Introduction, Foundation and intermediate) can be accessed by Tower Hamlets CCG and Tower Hamlets service providers. At least 50% of staff that make statutory assessments of special educational needs have received training on how to make adjustments in their approach and communication when dealing with people with ASD. However, gaps in training provision remain. Further work is required to ensure that all primary and secondary healthcare providers include autism training as part of their on-going workforce development, and Police, Probation and local court services receive training in ASD awareness. This should include those in the justice system who act as “appropriate adults” in support of people with ASD.

Recommendation - Training

- There is little data on the uptake of the Autism training that is available to staff. This should be improved to allow audit of training.
- Workforce training data should be collected from all statutory organisations and collated annually, gaps should be identified and plans developed to address shortfalls.
- Autism training plan should be included in the adults’ autism strategy

2. Identification and diagnosis of autism in adults, leading to assessment of needs for relevant services

Tower Hamlets Autism and Diagnostic Service (THAS) was established in May 2014 to provide a clear pathway to diagnose based on the ‘National Institute for Health and Clinical Excellence’ (NICE) guidelines for recognition, referral, diagnosis and management of adults on the autism spectrum. Referrals may be made to the service by GPs, Mental Health Service, Community Learning Disability Service (CLDS), Adult Social Care and self-referrals. The largest provider of referrals to the service is via mental health services (approximately 50%) with 25% from GPs and 17% from self-referral. Very few referrals have been received from CLDS and Adult Social Care services. The team meet weekly, however, waiting times for referral and assessment for the service may vary and diagnosis may take several weeks. The NICE recommendation is a maximum of 30 weeks. A total of 221 people have been referred to the service to end of 2015-16. 87% of people referred to the service are approved for diagnostic assessment and approximately 64% receive an ASD diagnosis. This indicates that most referrals to the service are appropriate. Adults given an ASD diagnosis are provided with an offer of a community care assessment and referrals to mental health and CLDS are made as appropriate.

Recommendation – A review of the pathways for referral to THAS to ensure that all stakeholders including GPs, CLDS, and Adult Social Care services are aware of the services and are confident regarding referral.

3. Planning in relation to the provision of services for people with autism as they move from being children to adults

Over the next 10 years it is likely that approximately 750 young people with a diagnosis of autism will become adults and, if appropriate, will transition from the responsibility of children’s to adults’ services. A level of guidance (via transitional plans) is required to be provided for children with ASD ensure those leaving school continue to receive support in adult life. A mechanism is in place for the transition between children’s and adults’ service however the numbers of young people referred into the adults’ service appears low in comparison to the number of young people with an ASD diagnosis. Only 23 young people in 2014/15 and 12 in 2015/16 were assessed as being eligible to access the service. Transition planning is reported as inconsistent. Anecdotal evidence suggests that the quality of transition planning may depend on proactive work by a service user’s parents or school. Feedback from parents suggests that reasonable adjustments are not always made. A restructure of CLDS and the Children with Disabilities service (CWD) is being undertaken. The social care element of CWD will be extending to age 25 in order to provide better continuity of care for young people, their families and carers.

Recommendation – The development of Adults’ Autism and Children and Young People’s SEND strategies should include planning for transition to ensure that continuity of care may be maintained. Further evaluation of the transition pathway may be required.

4. Local planning and leadership in relation to the provision of services for adults with autism

Planning of appropriate services relies on the collection of valid and reliable data such as the numbers of people with ASD who are referred to and/or accessing social care and/or health care. LBTH have started to collect data from social care assessments but it is not clearly reported. The introduction of the new data collections including the Short and Long Term support (SALT) collection and the Equalities and Classification framework (EQ-CL) creates better opportunities for disaggregating data for autism, so that the differing outcomes for this group could be identified and progress against the strategy measured effectively. Disaggregation would therefore enhance our understanding of how well social care is working for people with autism and help identify the areas where more action is needed¹⁹.

Recommendation - Data collection is vital to understanding need and the effectiveness of services. The proposed Autism strategy should include measures to improve the capture of relevant data.

5. Care and Support

In line with the guidance the Autism Diagnostic Service and Tower Projects First Start (Autism) Service act as identifiable contact points where people with autism, whether or not in receipt of statutory services, can get information signposting suitable entry points for a wide range of local services. The council has commissioned a one stop service for information, advice and advocacy for adults with support needs. This is delivered by Local Link – a consortium of nine local organisations. However there is no autism specific advocacy service currently available to residents and advocates do not receive autism specific training.

Recommendation - The proposed Autism strategy should include measures to promote adjustments to general council and public services to improve access and support for people with autism

6. Housing and accommodation

The needs of people with autism are not currently included in local housing strategies. Additionally Tower Hamlets Homes does not currently provide any specific training on autism to staff. However if they are made aware of any support need, including ASD, they provide a GTKY (Getting to Know You) visit to identify and to provide specific support needs to residents.

Recommendation – The Tower Hamlets housing strategy is in the process of being updated. The revised strategy should make reference to the specific needs of people with ASD. We should ensure that local housing offices all have at least one staff member who has training in autism to help people make applications and facilitate the housing needs of those with ASD.

7. Employment for adults with autism

Support is available via the Tower Hamlets Autism and Diagnostic Service for people who may benefit from support on gaining employment. Service users may be referred to the Tower Project Employment Service to support access to employment and training. At present 15% of users are

¹⁹ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/375431/ASCOF_15-16.pdf

provided with this support, but a national survey of people with ASD suggests that 53% say they would like support²⁰. Service users may also be supported into gaining vocational training, education and work placements as appropriate. A key element of the transition process is the focus on the education and employment of young people with ASD. It is not clear if the transition to adult services has a consistent approach to supporting services users into further education and employment.

Autism awareness training has been delivered to agencies working in the borough, but it is unclear the extent to which awareness training has been provided to employers and local job centres. Local employment support services for people with ASD are provided by the REAL information and guidance service (a local not for profit organisation).

Recommendation - The Autism strategy should ensure that transition planning includes a focus on the educational and employment needs of people with ASD as appropriate.

8. Working with the criminal justice system

Autistic people are more likely to be victims and witnesses of crime than offenders, and when autistic people commit offences, it may be due to social naivety or not understanding the implications of their behaviour. Due to the difficulties autistic people have with communication and social interaction, contact with the justice services can be extremely difficult. At present there is minimal engagement with London Community Rehabilitation Company and the Courts Service with regard to ASD. The National Probation Service in Tower Hamlets is engaged with the Safeguarding Adults Board and the planning for the 3 year Safeguarding Strategy 2015-2017. Discussions have been held between the local authority adult services and police regarding ASD. Representatives from the Police attend the Multi-agency Adult Safeguarding Hub, but this is not specific to autism and covers a broad spectrum of vulnerability. Police are also members of the Safeguarding Boards in the Borough.

Recommendation – Stakeholders from the Criminal Justice Sector should be included in the development of the Autism strategy to raise the profile of the needs of people with ASD within this sector.

6. What evidence is there that we are making a difference?

The Autism Act requires central government to review the Autism Strategy periodically to ensure that it remains an effective way to support people with ASD and their families. The feedback received under the last review of the strategy has been used to ensure that, when fully implemented, the strategy will make a difference to the quality of life of people with ASD

In April 2011 NHS London carried out an exercise to map progress on delivery against the Autism Act 2009, delivered through the introduction of a new Autism Self-Assessment Framework. In the findings published in March 2012, Tower Hamlets received a red rating against aims of the National Autism Strategy.

An LBTH Autism Project Team was established by Adult Services in 2011 to oversee the development of local autism services. This team articulated how the borough would implement the 2010 national autism strategy through an "Implementation Plan", which was agreed by the local authority and health commissioners. Progress was made in a number of areas. Key amongst these was the establishment of an Autism Diagnostic and Intervention service for adults in the borough in 2014, which is commissioned by the local authority to the East London NHS Foundation Trust using Better Care Fund (BCF) funding. However, some of the other aims of the

²⁰ Bancroft et al (2012). *The Way We Are: Autism in 2012*. London: The National Autistic Society

strategy were not carried out or were not carried out in full, largely due to the Autism Project Team discontinuing.

The 2014 Self-Assessment Framework exercise has demonstrated that progress is being made in implementing the Adult Autism Strategy in Tower Hamlets. Continued effort to implement the strategy will further improve ASD services.

7. Impact on Public Health Outcome Framework indicators

There are no PHOF indicators that are specific to autism but ASD services may have a positive effect on the following measures:

Indicator	Period	Count	Tower Hamlets	London	England
1.06i - Adults with a learning disability who live in stable and appropriate accommodation (Persons)	2014/15	385	67.00%	69.00%	73.30%
1.06ii - Percentage of adults in contact with secondary mental health services who live in stable and appropriate accommodation (Persons)	2014/15	-	91.60%	77.80%	59.70%
1.08i - Gap in the employment rate between those with a long-term health condition and the overall employment rate	2014/15	-	14.5	10	8.6
1.08ii - Gap in the employment rate between those with a learning disability and the overall employment rate (Persons)	2014/15	-	64.8	64	66.9
1.08iii - Gap in the employment rate for those in contact with secondary mental health services and the overall employment rate (Persons)	2014/15	-	65.1	66.2	66.1
1.18i - Social Isolation: percentage of adult social care users who have as much social contact as they would like	2014/15	-	39.80%	41.80%	44.80%

8. What is the perspective of the public on the support available to them?

User experience questionnaires are sent out to all appropriate individuals who have been open to the Tower Hamlets Autism and Diagnostic Service (THAS) since its formation. This included invitation to take part in focus groups to allow feedback on the service.

Since April 2014 adult social care assessments / reviews are able to record ASD as a “reported health condition”. However, it is unclear how complete the recording of ASD is on this system, and as such no feedback is currently available that is specific to ASD service users. The future intention is to co-produce the Autism Strategy with people with autism and their carers. As part of the strategy it is recommended that the Local Authority develops an on-going mechanism to hear the views of adults with ASD.

Recommendation – Data from the THAS and from social care assessments should be reviewed to ensure that commissioned services are meeting the needs of the population. People with ASD should be included as key stakeholders in the development of the Autism Strategy to ensure that it meets the needs of the service users and an on-going mechanism should be developed as part of the strategy to collect service user feedback on the services available.

9. What more do we need to know?

There are substantial knowledge gaps in the number of people with ASD known to health and

social care services (including on GP registers). Without the systematic recording of people with ASD in GP practices or using social care services, it is impossible to obtain accurate information about the group.

10. What are the priorities for improvement over the next 5 years?

Tower Hamlets should develop a local multi agency Autism strategy that meets the requirements of the National Adult Autism strategy. The Adult Autism Strategy and the Children and Young People’s SEND strategy should be linked to ensure transition planning for service users moving to adult from young people’s services.

11 Key contacts

- Peter Lamb, London Borough of Tower Hamlets, Public Health
- Adult Autism Service (Tower Hamlets) Email - elt-tr.Tower-Hamlets-Autism-Service@nhs.net Website - <https://www.elft.nhs.uk/service/11/Adult-Autism-Service-Tower-Hamlets>

Factsheet info

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Factsheet signoff

Date signed off by Senior JSNA leads	Signed off by (Public Health Lead (name))	Flora Ogilvie	Date signed off by Strategic Group:		Sign off by Strategic Group (name):	
	Signed off by (LBTH Lead if different to above(name)):	Barbara Disney				