

# Autistic Spectrum Disorder: Factsheet

## Tower Hamlets Joint Strategic Needs Assessment 2010-2011

### Executive Summary

People with Autistic Spectrum Disorder (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.

There is currently work underway to implement the national autism strategy for adults in Tower Hamlets in accordance with Department of Health guidance. The first priority areas are:

- Autism awareness training (for all health and social care staff).
- Diagnostic pathways.
- Transition to adult services.
- Planning and leadership/ needs assessment (with a strong focus on filling some of the extensive knowledge gaps around adults with autism in the borough).

### 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. 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)

ASD is often under-diagnosed, under-reported and misdiagnosed, largely due to the social and communication difficulties listed above.

### 2. What is the local picture?

There are thought to be around 1,910 adults with ASD in Tower Hamlets in 2011, approximately 765 of whom do not also have a learning disability.

Recent estimates suggest that there are approximately 400,000 adults with Autism in England (approximately 1% of the population<sup>1</sup>). Prevalence is thought to be higher among men (1.8%) than among women (0.2%), which is consistent with patterns found in childhood population studies.

<sup>1</sup> *Autism Spectrum Disorders in adults living in households throughout England: Report from the Adult Psychiatric Morbidity Survey 2007*, published by the Health and Social Care Information Centre in 2009.

It is thought that approximately 40% of these individuals do not have additional learning disabilities (Baird et al., 2006; Brugha et al, 2009). This group is often referred to as having higher-functioning autism or Asperger's syndrome, and is the main focus of this factsheet.

This equates to around 1,910 adults in Tower Hamlets with ASD in 2011 and 765 adults with ASD and no additional learning disability.

The National Autistic Society states that 'estimates of the proportion of people with autism spectrum disorders (ASD) who have a learning disability, (IQ less than 70) vary considerably, and it is not possible to give an accurate figure. 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.'

**Table 1 Different estimates of ASD nationally and in Tower Hamlets**

Estimate	Prevalence or number of people	Source
Prevalence of ASD in adults (national)	1.0%	<i>Adult Psychiatric Morbidity Survey 2007</i>
Prevalence of ASD in adult men (national)	1.8%	<i>Adult Psychiatric Morbidity Survey 2007 – Men</i>
Prevalence of ASD in adult women (national)	0.2%	<i>Adult Psychiatric Morbidity Survey 2007 – Women</i>
Number of adults in Tower Hamlets with ASD (all)	1,910	National prevalence and local population estimates, 2011 <sup>2</sup>
Number of adults in Tower Hamlets with ASD and no learning disability	765	Baird et al., 2006; Brugha et al, 2009; local population estimates, 2011
Number of adults with ASD known to social care in Tower Hamlets	50-60	National Audit Office Census
Number of children in Tower Hamlets with ASD (all)	220	Special Educational Needs Data, 2010

Using the national estimated prevalence rates from the Adult Psychiatric Morbidity Survey (2007) applied to GLA population estimates, the number of adults with ASD (including those with an IQ below 70) in Tower Hamlets will increase by around 9% over the next five years, from 1,910 in 2011 to 2,085 in 2016. This number is expected to increase by 19% over a ten year period, from 1,910 in 2011 to 2,265 in 2021.

In 2010/11<sup>3</sup> there were 205 children aged 18 and under in Tower Hamlets with an Autistic Spectrum Disorder alone, and a further 65 children with an ASD in combination with another disability.

**Table 2 Number of children with Autistic Spectrum Disorder in Tower Hamlets**

Disability	Number of Children
ASD	205
ASD with Severe Learning Disability	3

<sup>2</sup> Estimates based on the above national prevalence rates from the Adult Psychiatric Morbidity Survey (2007) and applied to GLA population estimates for 2011.

<sup>3</sup> Tower Hamlets Special Educational Needs Data, 1<sup>st</sup> April 2011.

ASD with Behavioural/ Social/ Emotional Difficulty	2
ASD with Moderate Learning Disability	16
ASD with Other Disability	2
ASD with Physical Disability	1
ASD with Speech, Language and Communication Needs	39
ASD with Specific Learning Disabilities	2
Total ASD in Tower Hamlets	270

**Source: Tower Hamlets Special Educational Needs Data, 2011**

Emotional and behavioural difficulties associated with ASD often worsen dramatically during adolescence. In 2011 there are 80 young people aged between 13 and 18 years (inclusive) with ASD in Tower Hamlets.

ASD has been recorded more accurately in Special Educational Needs (SEN) data since 2007. Data available from 2007 onwards illustrates a disproportionate rise of 69.8% in the number of children aged 18 and under with ASD in Tower Hamlets, from 159 children in 2007 to 270 children in 2011. This compares to just a 5.4% increase in the total population aged 18 and under over the same period of time. It is difficult to ascertain whether this relates to real increases in incidence of ASD or improved recording of SEN data.

In March 2008, it was estimated that there were approximately 50-60 adults who meet London Borough of Tower Hamlets FACS eligibility criteria with ASD known to services<sup>4</sup>. It may be that this simply corresponds with the number of people with a moderate or severe learning disability who have ASD and receive services for their learning disability. It is likely however, that a substantial number of people who have ASD in the borough have not received a correct diagnosis, or that the diagnosis has not been correctly recorded.

There are currently no GP registers for autism in Tower Hamlets, which makes it difficult to establish the number of adults with a diagnosis.

### 3. What are the effective interventions?

The National Audit Office (NAO) report '[Supporting People with Autism through Adulthood](#)' (2009) highlights the importance of Local Authorities and NHS Trusts systematically recording numbers of both adults with 'low functioning' and those with 'high functioning' Autism.

The NAO report and [research conducted by the National Autism Society \(NAS\)](#)<sup>5</sup> suggest that there are gaps in local training, planning and service provision for people with ASD across the country.

NAS request that a 'Specialist Autism Team' (SAT) be established in every local authority, jointly funded and delivered by health and social care<sup>6</sup>. As well as improving diagnostic services, the SAT would provide ongoing training to health and social care staff, provide sign-posting and brokerage, provide low level services (to reduce social exclusion and facilitate employment), and support social services with care assessments in more complex cases. It is also recommended that each locality set up an Autism Planning Group, comprising learning disability and mental health commissioners and managers, representatives from the SAT, voluntary sector and children's services, and adults with ASD and carers for those with ASD. The Planning Group would liaise with the JSNA process to develop appropriate services to meet the needs of the local population with ASD.

The national autism strategy [Fulfilling and Rewarding Lives](#) was published in March 2010. The long term vision of the strategy is that "All adults with autism are able to live fulfilling and rewarding lives within a society that

<sup>4</sup> Taken from return to the NAO Census *Supporting People with Autism through Adulthood*

<sup>5</sup> Rosenblatt, Mia. (2008) *I Exist: The message from adults with autism in England*. London: The National Autistic Society.

<sup>6</sup> Tom Madders (2009) *A Better Future: consultation response from the National Autistic Society*.

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”<sup>7</sup>.

[Statutory guidance](#) on implementing the strategy<sup>8</sup> was published in December 2010, and highlights four priority areas:

1. **Autism awareness training** for health and social care staff
  - General autism awareness training should ultimately be available for everyone working in health and social care.
  - Specialised training for staff working in key roles, such as GPs, those responsible for conducting community care assessments, and those in local leadership roles.
2. **Identification and diagnosis** of autism in adults, leading to assessment of needs for relevant services (including carer's assessment)
  - Clear pathway should be put in place locally for diagnosis of autism, from initial referral to assessment of needs.
  - National Institute for Health and Clinical Excellence (NICE) is developing new clinical guidelines for adults with autism, setting out a model care pathway - to be published July 2012.
  - After diagnosis and assessment of need, the NHS body or NHS Foundation Trust providing healthcare to the adult should inform (with consent) the relevant local authority adult services department promptly to ensure that a community care assessment (if desired) is carried out within a reasonable time period.
3. Planning in relation to the provision of services to people with autism as they move from being **children to adults** (with Connexions services responsible for overseeing delivery of the transition plan)
  - There is a forthcoming Department for Education Green Paper on improving the support available to children with Special Educational Needs (SEN) and disabilities, and their families.
  - Local authorities must arrange assessments of needs and the provision that will be required to meet those needs for all young people with statements who are thinking of going on to further education or training. The most effective transition support is available from age 13 to 25.
  - Adult and children's services should work with schools, families and young people to identify support needs during transition and enable positive outcomes.
    - Transition planning should be individually tailored and include career preparation up to age 16 and plans for education, employment, training, transport, housing and leisure from 16 to 19 and beyond.
    - Plans should be reviewed and updated each year.
4. **Local planning and leadership** in relation to the provision of services for adults with autism (including JSNA, reasonable adjustments, etc)
  - The Equality Act 2010 requires all public service organisations to make reasonable adjustments for people with disabilities. This includes people with autism.
  - Adults with autism who are FACS eligible should be able to access personal budgets and direct payments, in line with the assessment of their needs.
  - Local authorities are encouraged to explore how to support volunteer and community groups, and social enterprises, in planning and commissioning services locally (with a particular focus on advocacy and buddy schemes).

#### 4. What is being done locally to address this issue?

##### Primary Care

GPs in Tower Hamlets currently do not systematically record presence of autism to keep a register (as is the case

<sup>7</sup> Department of Health (2010) Fulfilling and Rewarding Lives: The Strategy for adults with autism in England, p.6.

<sup>8</sup> Department of Health (2010) Implementing "Fulfilling and Rewarding Lives": Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy.

for patients with a learning disability).

## Secondary Care

Adults may currently be referred by GPs or Consultant Psychiatrists to the [Behavioural Disorders Service](#) at Bethlem Royal Hospital (South London and Maudsley NHS Foundation Trust) for diagnosis. The service also provides evidence-based treatment and collaborative care for adult males who present with high functioning autism spectrum disorder and co-morbid mental health or behavioural problems. The service is one of only two NHS units in the country that specialise in this area.

There is no clear diagnostic pathway in place for adults with autism in Tower Hamlets.

## Community services

There are no specific community health services for adults with autism in Tower Hamlets. The Community Learning Disabilities Service (CLDS) supports some adults with autism and learning disabilities but not those without a learning disability. Some CLDS clients who meet FACS eligibility criteria receive social care whilst others will only receive input from CLDS health teams.

## Social Care and Prevention

### Services for Children and Young People with autism and their carers

- [Mindbuilders Project](#) (*Bethnal Green*): Early Bird Intervention Autism Project; a family centred approach to autism, offering parent groups and individual support work.
- [Parents Advice Centre](#) (*Stepney*): providing information, support and advice to parents and carers of children with special educational needs.
- *Child Development Team (Mile End)*: providing assessment and co-ordination service for children under the age of 18 with multiple disabilities and their families. A referral criterion is evidence of delay in two or more areas of development.
- [Phoenix Outreach Service](#) (*Bow*): team of specialist teachers, teaching assistants and speech and language therapists to work with children on the autistic spectrum. Supporting children aged 3-16yrs with ASD in mainstream education.
- *NAS Autism Support Tower Hamlets (Spark Centre, Bethnal Green)*: providing information, advice and support to parents, carers and young people with ASD; offering help with behavioural, emotional and practical challenges that living with a child with ASD can present.
- *Sparkle Under Fives Play and Activity Service*: providing weekly sessions for children aged 18 months to 5 years who have a disability, including ASD.
- *'Aut and About'*: providing group based activities in the community on Saturdays for children aged 8-13 years (junior group) and young people aged 14-19 years (senior group) with ASD- has a long waiting list.
- *Autism Parents Support Group (Phoenix School, Bow)*: providing support to parents and carers of autistic children.

### Services for Adults with autism and their carers

- [The Tower Project, First Start](#) (*Isle of Dogs*): Day service for FACS eligible adults with ASD who display challenging behaviour. Provides day trips, leisure activities, sensory room, and 1:1 support for every service user.
- [National Autistic Society Befriending Scheme](#): Befriending service for children or adults with autism and their families.
- [The Carers Centre](#): providing support to carers, including those of people with ASD.

London Borough of Tower Hamlets has a duty to support adults with social care needs assessed as either critical or substantial (in line with FACS eligibility criteria). Many adults with ASD will not meet social care eligibility thresholds. It is therefore important that they are adequately supported to access 'universal' and mainstream

services such as those facilitating social inclusion, e.g. advocacy, information and advice, and employment support.

A steering group has been established to explore implementation of the national autism strategy in Tower Hamlets. This group is focusing on training opportunities for health and social care professionals and on mapping diagnostic pathways across Inner North East London.

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

First Start is a service for FACS eligible adults, currently running at maximum capacity with 20 service users attending five days per week<sup>9</sup>. Service users attending First Start all present challenging behaviour and require 1:1 support, limiting capacity with current staff levels. The service has recently started to accept referrals of children of school age who have been excluded from mainstream education. Four young people currently attend First Start. Some referrals are also accepted from neighbouring boroughs, including Hackney and Newham. Despite growing interest from parents, referrals are only accepted from social services. The majority of these come from CLDS, with some from Mental Health services. There is a long waiting list for First Start, and current capacity does not meet the growing demand for services for adults with ASD in Tower Hamlets.

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

Over 100 people with autism (or suspected of having autism), carers, and professionals in Inner North East London contributed to a consultation by East London NHS Foundation Trust on the national autism strategy (in 2009). The majority of this consultation focused on the needs of people with High Functioning Autism or Asperger's Syndrome (AS) and were grouped into the themes below.

### Carers

- Most carers of people with AS are not eligible for Carers Allowance, due to the low number of hours that they regularly provide formal care. However, most provide a large amount of informal care, e.g. emotional support. This often takes place by telephone if the person with AS and carer do not share an accommodation.
- People don't understand the family isolation
- There is a high cost because parents can't work
- Carers are exposed to a lot of 'subjective' stress.

### Respite

- Traditional respite is not always geared towards people with AS, because they focus on respite away from the home or away from their carers.

### Communication

- Services need to be able to understand the communication needs of people with ASD. Technology should be used across the spectrum. There are people with little or no verbal communication, who use augmented communication. People prefer to use email rather than the telephone.
- Documentation could be more appropriate. Most seems to be geared towards mental health or physical disabilities.

### Parenting

- There are no specific services for people with autism who are parents. They often require parenting support or information.

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<sup>9</sup> 2010

Other comments included:

- Frustration with an over-emphasis on 'functioning level' terminology and on IQ during diagnosis;
- Frustration with having a diagnosis but no services available;
- Experience of mainstream services as having 'no patience' for people with Asperger's Syndrome.
- There needs to be better awareness of ASD amongst health and social care professionals in Tower Hamlets, in order to facilitate diagnosis and improve accessibility of services.

## 7. 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. It is possible that further research at a national level will allow local estimates of information such as:

- Need for support to live independently
- Age profile of people with autism in the area
- Employment status
- Likely to need employment support in order to work
- Placed in the area (and funded by) other local authorities
- Placed out of borough
- In hospital
- Living at home independently and not receiving health and social care services
- Living with older family carers
- Gender
- Ethnicity
- Religion
- Sexual orientation

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

There is currently work underway to implement the national autism strategy in Tower Hamlets in accordance with Department of Health guidance. The working group established locally is chaired by the Adult Health and Wellbeing Service Head for Disability and Health, and membership includes representation from commissioning, psychiatry, social work and strategy and policy. The first priority areas are:

- Autism awareness training
- Diagnostic pathways
- Transition to adult services
- Planning and leadership/ needs assessment

## 9. Key Contacts & Links to Further Information

- For general JSNA queries email: [JSNA@towerhamlets.gov.uk](mailto:JSNA@towerhamlets.gov.uk)
- Factsheet contact Natalia Clifford, Public Health Strategist: [Natalia.clifford@thpct.nhs.uk](mailto:Natalia.clifford@thpct.nhs.uk)

Information for professionals on how to refer to the Behavioural Disorders Service:

<https://www.national.slam.nhs.uk/wp-content/uploads/2010/09/Referral-Guide-Behavioural-Disorders.pdf>

Poster produced by South London and the Maudsley NHS Foundation Trust and the Estia Centre providing basic advice to professionals supporting people with autism:

<http://www.estiacentre.org/docs/ASCposter.pdf>

National Autistic Society, Tower Hamlets Befriending scheme, tel. 020 8980 0093, [THamsBefriending@nas.org.uk](mailto:THamsBefriending@nas.org.uk)

Belinda Foster, Autistic Day Service Manager, First Start, The Cedar Centre, 17 Arden Crescent, Timber Wharves, Isle of Dogs, London, E14 9WA, tel. 020 7538 4600, [Belinda@towerproject.org.uk](mailto:Belinda@towerproject.org.uk)

Tower Hamlets Job Enterprise Training, Unit 2, Candy Wharf, 22-32 Copperfield Road, E3 4RL, tel. 020 8980 3500, <http://www.towerhamlets-jobhunters.org.uk/>

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		<b>Signed off by (LBTH Lead):</b>	Deborah Cohen				