

<b>Healthier Communities Select Committee</b>			
Title	Implementing the National Autism Strategy in Lewisham		
Contributor	Executive Directors for Community Services and Customer Services	Item	5
Class	Part 1 (open)	2 December 2014	

## **1. Purpose**

- 1.1. This report provides an update for the Healthier Communities Select Committee on the progress of implementing the National Autism Strategy since July 2014.

## **2. Recommendations**

- 2.1. It is recommended that Members of the Healthier Communities Select Committee:
- 2.1.1 Discuss and note the contents of this update
- 2.1.2 Support local implementation work

## **3. Background**

- 3.1. Directors of Adult Social Services were requested by the Department of Health to take forward the second self-assessment exercise for the implementation of the Adult Autism Strategy.
- 3.2. It was a requirement of this process that submissions were discussed by the Local Health and Well Being Board. The Lewisham Autism Self Assessment Framework was discussed at the Health and Well Being Board on 19th November 2013.
- 3.3. At the request of the Chair a progress report was submitted to the Health and Wellbeing Board on 3rd July 2014. As specified by the Chair there was a particular emphasis on the inclusion of adults with autism in the local housing strategy and more detail on how Lewisham Housing was working to identify a range of housing to support residents with particular needs.

## **4. Progress since July 2014**

- 4.1. **The inclusion of autism in the local Joint Strategic Needs Assessment and improving the data collected regarding numbers of adults with autism in the Borough.**
- 4.1.1 In June 2013 Dr Ratna Ganguly, GP Vocational Trainee, Lewisham PublicHealth produced a report making recommendations for improvements to data collection for adults with autism.
- 4.1.2 In Lewisham the majority of general practices use the same medical information software system, known as EMIS Web, to record patient data. All conditions or diagnoses utilise Read-codes as a method of recording. Although there are no

autism registers kept by GPs, the numbers of people with a known diagnosis of autism registered with a GP may be sought by auditing the codes. The report recommended that there should be a regular audit of people diagnosed with autism utilising the "READ" codes for Autism. However, to ensure that this audit was as accurate as possible there was a need for training for GPs/Practice staff in recognising/ identifying autism and appropriate referral routes to autism specific services.

- 4.1.3 In July 2014, Lewisham CCG commissioned Endersby Training to deliver two sessions on "An Introduction to Autism Spectrum Condition (ASC) for GPs in Lewisham".
- 4.1.4 The aim of the training was to enlighten GPs in the London Borough of Lewisham about autism and to give them more confidence in being able to refer their patients for a formal diagnosis or to seek help from an autism specialist.
- 4.1.5 The training was attended by 29 GPs (out of a total of approx. 200 GPs in Lewisham) and was evaluated as being 95% excellent or good. Comments given in the evaluation were overwhelmingly positive with GPs particularly valuing the insight/expertise of the trainer and stating that attendance on the course would definitely improve their practice in the identification of patients with possible autism and relationship with patients already diagnosed.
- 4.1.6 Lewisham CCG is planning to engage with its membership regarding the first audit of people diagnosed with autism using the READ codes in early 2015.

## 4.2. **The Accommodation Needs of People with Autism**

- 4.2.1 The Housing and Autism Project Group has met three times since July 2014.
- 4.2.2 The Group is chaired by Jeff Endean (Housing Strategy and Programme Manager) and supported by Dave Shiress (Housing Strategy Officer).
- 4.2.3 Since September, Dave Shiress has been exploring opportunities for providing housing to adults with autism living in Lewisham. At the last meeting (6th October 2014) three options were discussed:

### Option 1

- 4.2.3.1 Finding an empty Housing Association property where a current support specific service is being or has been decommissioned. A specialist autism provider such as Burgess Autistic Trust could enter into a lease with the H.A. This type of accommodation would be suitable for adults with low support needs. Support workers could be funded by an element of service charge covered by Housing Benefit.

### Option 2

- 4.2.3.2 Finding a Housing Association partner to work on new build options. Possibly a cluster of 5/6 flats with space for staff. This would require accessing capital funds for 'specialised housing' (probably GLA or Department of Health).

### Option 3

- 4.2.3.3 Officers from LBL Housing to run an awareness session for members of CLASH and professionals working with people with autism on housing options, such as how to access the housing register, how to access the private rented sector and how shared ownership schemes work.
- 4.2.4 So far efforts to identify a housing association provider to take forward options 1 and 2 have been unsuccessful. Whilst the Council acknowledges that a need for accommodation for adults on the autism spectrum exists, in the current environment it is difficult to find a housing provider willing and able to help meet this need.
- 4.2.5 Every effort will continue to find a Housing Provider and every other possible options/solutions will continue to be developed and discussed at future meetings (date of next meeting 1<sup>st</sup> December 2014)
- 4.2.6 Lewisham Clinical Commissioning Group currently commissions Burgess Autistic Trust to provide a Lewisham Information, Advice and Support Service for Adults with autism/asperger's Syndrome.
- 4.2.7 Burgess Autistic Trust (BAT) has a portfolio of accommodation in Bromley and for BAT, extension on this portfolio into Lewisham is a logical next step. Though finding a housing association partner is not without its difficulties, the existence of BAT presents a genuine opportunity to increase housing provision for people with autism in Lewisham.

### **4.3 Autism Innovation Fund**

- 4.3.1 In August 2014 the Department of Health launched a time limited Autism Innovation Fund. The aims of the fund were to help drive creative and cost effective solutions and identify good models of practice that could be replicated in other areas.
- 4.3.2 There were four areas where the Government invited proposals:  
These were;
- Advice and Information
  - Gaining and growing skills for independence
  - Early intervention and crisis prevention
  - Employment, particularly involving the use of apprenticeships
- 4.3.3 Organisations in Lewisham submitted their bids independently and were not obliged to share these with the Local Authority or confirm that they had submitted a bid. Six organisations contacted officers to express an interest in the bidding process. Ideas put forward included:
- Apprentices/work placements
  - Developing a computer application for ASD individuals
  - Innovative technology – all linked to gaining independence
  - "Experts by Experience" training programme (co-developed/delivered by adults with autism)
  - Training workshops,

- Provision of a training flat
- Autism Awareness Training
- Advocacy
- Support ASD individuals into volunteering.
- Support volunteers to work as buddies/befriending service for people with Autism

4.3.4 Due to the large number of bids received by the Department of Health, the evaluation process and decision making were significantly delayed. The London Borough of Lewisham was notified on 7th November 2014 that no organisations in Lewisham were successful in securing funding.

4.3.5 A small and non-recurrent grant of £18,500 has been awarded to every Local Authority in England. The purpose of this grant is to provide Councils with a contribution to the cost of supporting work around helping people with autism in line with “Think Autism” This funding could be used to purchase new electrical equipment or IT developments, or for making environments used by people with autism such as public buildings more autism friendly.

4.3.6 Plans on how this money will be used, must be discussed with local stakeholders (including people with autism) and submitted to the Department of Health by the 12th December 2014.

## **5. Conclusions**

5.1. Lewisham is looking to establish a community that accepts and understands autism and which has an infrastructure that provides opportunities for adults with autism/asperger’s syndrome to live fulfilling and rewarding lives.

5.2. Officers will continue to work with partners in Health, Voluntary Sector and those with autism and their Carers to ensure we maximise opportunities to achieve the above aim.

5.3 Regular updates on progress will be provided to the Health and Wellbeing Board and to the Healthier Communities Select Committee on request.

## **Background Documents**

[Health and Wellbeing Board Report – 19th November 2013](#)

[Health and Wellbeing Board Report – 3rd July 2014](#)

Self Assessment Frameworks submitted in 2013 -  
[www.improvinghealthandlives.org.uk/projects/autism2013](http://www.improvinghealthandlives.org.uk/projects/autism2013)

[Think Autism Fulfilling and Rewarding Lives, the strategy for adults with Autism in England: an update. April 2014](#)

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## Appendix 1

Autism in Lewisham

By Dr Ratna Ganguly:

General Practice Vocational Training Scheme (GPVTS) in Public Health

**June 2013**

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## 1. Aims and Objectives

DoH Guidance (December 2010) Implementing “Fulfilling and Rewarding Lives” calls on Local Boroughs to develop their own Commissioning Plan around services for adults with autism that reflects the output of the Joint Strategic Needs Assessment (JSNA), based on effective needs analysis underpinned by good information about adults with autism in the area and all other relevant data around prevalence. The purpose of this report is to establish the current position in Lewisham in regard to information on Adults with Autism and make recommendations if required to enable a comprehensive JSNA to be completed on Adults with Autism in the future.

Aim: To gather existing information on adults with autism held by different health and social care organisations in Lewisham. To review this data together with that included in the 2009 Autism needs analysis-The needs of adults with an Autism Spectrum Disorder (particularly Asperger Syndrome and make recommendations to enable a comprehensive JSNA to be completed on Adults with Autism in the future.

### Objectives:

- Contact frontline services in contact with adults with autism and gather data held by them.
- Hold discussion with managers of social care services and gain feed back on service provision.
- Review the 2009 – Autism needs analysis-The needs of adults with an Autism Spectrum Disorder (particularly Asperger Syndrome) by Sadie King, and identify any areas for further examination
- Document available information on services for adults with autism in Lewisham.

## 2. Methods

Health, social care and voluntary services were contacted to provide data on the number and needs of adults with autism in Lewisham they supported. These organisations included: The Autism Diagnosis Centre at the Ladywell Unit; SLAM (South London and Maudsley Mental Health Trust); the Transition Services; Adult Social Care/Social Care

Assessment and Information Team (SCAIT); Adult Learning Disability Team; The Burgess Autistic Trust and Campaign in Lewisham for Autism Spectrum Housing (CLASH).

All services and groups were requested, in writing, to provide details pertaining to the service, epidemiological data, and information on education, housing status, carers and health matters of Lewisham's adults with autism.

A search was carried out at the Lewisham Clinical Commissioning Group (CCG) to elicit read codes used in the EMIS medical information software system, used to document autism diagnoses in general practice.

Two meetings were held with members of Adult Social Care and Disability services to elicit difficulties with data gathering within the Integrated Adult Services (IAS) electronic service user records system and to discuss any issues in relation to service provision.

This report is based on the data generated and a review of the Autism Needs Analysis (2009).

### **3. Facts and Figures**

#### **3.1 Definition**

Autism refers to a group of enduring developmental disorders which range from mild characteristics, in which people are able to live independent lives, to severe autism whereby considerable specialist support is required<sup>1</sup>. For this reason it is considered to be a spectrum disorder or preferentially known as Autistic Spectrum Condition (ASC).

The diagnosis of Autism is based on the criteria set out by the Diagnostic and Statistical Manual of Mental Disorders (DSMIV) and the International classification of diseases and related health problems (ICD10). The former classification system is undergoing revision. All autistic people are known to have a "triad of impairments" of which the degree of impairment may vary<sup>2</sup>. The criteria include;

1. Difficulties in reciprocal social interaction with difficulties recognising or comprehending how others feel and expressing their own emotions.

2. Impaired communication skills, a deficit or complete lack of spoken language development. Difficulties initiating and sustaining conversations. Repetitive or idiosyncratic speech.

3. Limited, stereotyped and repetitive patterns of behaviour, interest and activities. Which include intense preoccupations with matters of interest, rigid adherence to ritual and routines. Physical repetitive manners, such as flapping of the hands.

Autistic people may also experience sensory over or under sensitivity in one or more sensory modalities. Other conditions may also co-exist with autism (see appendix 2).

### **3.2 Prevalence:**

In children, Baird et al (2006) estimated the total prevalence of Autistic Spectrum Disorder (ASD) to be 1.16% of the UK's total population<sup>6</sup>. Subsequent studies estimate the prevalence to range from 1.5% to 2.1%<sup>7, 8</sup>. However the National Autism Plan for children in 2003 noted that children with high functioning autism had living skills that enabled them to lead a relatively 'normal' life, and were not picked up by studies. These children were likely to be diagnosed later in life. Therefore, the prevalence figure within child populations is likely to underestimate the true prevalence<sup>9</sup>. Baird et al, in their report about the prevalence of autism spectrum among a cohort of children in South Thames, noted that 55% of those with ASD had an IQ below 70%<sup>4</sup>.

The estimated prevalence for autism in adults has been variable due to differences in the way autism was diagnosed and defined<sup>3</sup>. Relatively newer reports suggest a prevalence of 400, 000-500, 000 adults in the UK have autism, or 116 per 10,000<sup>4</sup>. The prevalence figures for adults with autism have been based upon collating data on adults scoring highly on the Autism Diagnostic Observation Schedule, which aims to identify positive cases of autism<sup>10</sup>. The rate of autism is higher among males than females, 1.8% to 0.2% respectively. This corresponds with figures found in childhood population studies.

Observations made by the National Autistic Society estimated that figures for people with autism with coexisting learning disabilities, (IQ less than 70) varied greatly and that it is not possible to give accurate figures. Many able people with ASD may never come to the attention of services, as they have learned ways to overcome difficulties with communication and social interaction. These people may be in fulfilling vocations that



suit their needs and talents. Other intellectually able adults may require support from services, as a result of particular impairments that relate to difficulties in their social interactions. Such impairments may have an impact on their lives, in that they reduce the individuals' chances of employment and achieving independence.

Twenty to thirty per cent of adults with learning disabilities, who are known to adult social services, have a diagnosis of autism, totalling 35,000–58,000 people across England<sup>5</sup>. Better understanding of the nature of autism among referrers and clinicians who make the diagnoses i.e. psychiatrist has contributed to increased trends of ASC<sup>1</sup>.

### **3.3 The key inequalities**

Due to the varying degrees of ability and disability, juxtaposed with the absence of usual development, and the presence of unusual skills, ASC is greatly misunderstood. This ultimately affects people's decisions about support and help for adults with autism<sup>10</sup>.

Research has shown that 30% of people with disabilities live below the poverty-line and that the health outcomes for disabled people are poorer than those for the general population, this figure includes adults with autism<sup>11</sup>.

Adults with ASC lead more restricted lives, are less independent and experience higher unemployment, stress, health problems, sleep disorders, bullying, discrimination, neglect and vulnerability<sup>13, 14</sup>. A large number of adults with autism continue to reside with their families rather than independently in their own homes<sup>15</sup>.

The 2008 campaign "I Exist" initiated by the National Autistic Society involved a survey of adults with autism, parents and carers to identify the needs of 1400 adults with autism. Furthermore, in-depth interviews of adults with autism and surveys of PCTs/local authorities were carried out<sup>12</sup>. The research found that 63% of adults with autism did not have adequate support to meet their needs and 33% of people experienced severe mental health problems as a result. Only 15% of adults with autism were in full term paid employment and 60% of parents stated that they lacked adequate support, which led to higher support needs later on in their lives.

The 2009 "Don't write me off" survey, a follow-up of the "I Exist" campaign, noted that of 323 respondents, over half spent time with neither a job nor benefits, some for over ten

years. Over 79% of those on Incapacity Benefit wanted employment. A total of 82% of adults with autism felt that they needed help when applying for benefits<sup>10</sup>.

A report by Kings College in London estimated the economic cost of autism in adults to be £25.5 billion per year (59% in services, 36% in lost employment and 5% in family expenses). Estimated average annual costs for adults with a high-functioning ASD range from £33,000 to £88,000<sup>5</sup>.

The issues of poor understanding and awareness of autism is reiterated in a report by the University of Sussex, who were commissioned by Social Care Institute for Excellence (SCIE) to assess the needs of people with autism and their families. Their findings included the following<sup>1</sup>:

- There is a lack of awareness about autism, among some social care staff, other professions and society in general.
- The 'invisibility' or lack of physical signs of autism leads to Adults with autism' interaction to be considered odd, ill-mannered or alarming.
- Completing forms or taking part in social care assessments for benefits, requires the need for good social communication and social interaction, which people with autism lack. Thus creating another barrier to accessing services/support.
- Some people with autism are talented and very articulate. In the absence of learning disabilities, professionals have assumed that they do not need social care support. People with learning difficulties are supported by learning disabilities teams. Adults with Asperger Syndrome with IQs above 70, with no mental illness, are excluded from social care services as well as learning disability and mental health services.
- A large number of services including drug and alcohol services, feel unequipped to deal with adults with autism and lack confidence in referring people with autism to specialized services. However these specialist autism services are scarce, and can be geographically or financially difficult to access.
- Many social services have generic teams, which have separate teams for initial assessment and for ongoing care. This lack of consistency in staffing can be difficult for people with autism.

### **3.4 Targets and performance:**

The National Audit Office report “Supporting People with Autism through Adulthood” examined the available services including health and social care, education, benefits and employment support for adults with autism and their carers<sup>5</sup>.

NHS organizations, local authority social services offer little data on the number of adults with autism in their area. This in turn diminishes their ability to identify need and facilitate planning and commissioning to bring about appropriate services. In the report only 18% of responding Local Authorities and NHS partners were able to provide detailed information on the number of adults with low functioning autism receiving services. In total, 12% of local authorities were able to offer data on high functioning groups, with 35 % providing estimate figures for adults with autism.

Furthermore, 20% of GPs reported that they kept registers of patients with autism. However only 12 % kept registers of all patients falling within the autism spectrum, 6% had registers of patients with high-functioning autism, and 2% registered patients with low-functioning autism

### **3.5 National strategies**

The 2009 Autism Act was the first of its kind, being a disability specific law in England. It placed pressure on the government in regards to the following area

1. Produce an adult autism strategy by 1 April 2010 (Fulfilling and Rewarding lives)– This was published on the 2<sup>nd</sup> March 2010
2. To issue statutory guidance for local authorities and local health bodies on supporting the needs of adults with autism by December 2010. This guidance was published on 17 December 2010.

The Fulfilling and Rewarding Lives Strategy promoted key actions:

#### **1. Improved training of frontline professionals in autism**

Firstly there is a need to improve training of frontline professionals, as awareness and understanding of autism has been poor in the past. A recent report by the National Audit Office elicited that 80% of GPs did not feel that they had a comprehensive understanding of autism. The government has committed to providing £500,000 improve training among

frontline professionals in health and social care.

## **2. The development of local autism teams**

There were calls to develop local autism teams stressing the importance ensuring that adults who have an IQs above 70 (ineligible for support from the learning disability team) or with no significant co-existing mental illness (and thus also ineligible for support via mental health teams) do not “fall in the gap” created by traditional service boundaries.

## **3. Actions for better planning and commissioning of services, (including involving people with autism and their parents/carers)**

Improved planning and commissioning of services, including involving people with autism and their parents/carers is required including JSNAs to initiate the appropriate development of local services to meet the needs of adults with autism and encourage the development of local autism partnership boards, that bring together different organisations, services and stakeholders locally and set a clear direction for improved services.

## **4. Actions for improving access to diagnosis and post-diagnostic support**

Improving access to diagnosis and post-diagnostic support must be tackled. Furthermore, many GPs have identified that they do not have the expertise to identify people with suspected autism for referral even if there was a diagnostic centre for referrals. The paucity in local diagnostic services and a lack of formal diagnosis among adults serves as a barrier to accessing support and services

## **5. Leadership structures at national, regional and local levels for delivery**

A lack of leadership at all levels on autism has been a key barrier to the development of services for adults with autism. Both directors of adult social services, commissioners and ministers for care services should be clear about the commissioning responsibilities for adults with autism.

## **6. Proposals for reviewing the strategy to make sure that it is working**

It is important that the implementation of the strategy should be reviewed to make any important revision. The government has addressed this by committing to a formal review of the strategy in 2013 and to take action if the strategy is not delivered.

Furthermore in 2010 the department of health set out guidance “Implementing Fulfilling and Rewarding Lives: Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy. The government identified seven quality outcomes and three service ambitions that go beyond the remit of health and social care, tackling areas such as housing, employment and autistic adults’ satisfaction of public services<sup>18</sup>.

#### **4. Adults with Autism in Lewisham:**

##### **4.1 Estimated Prevalence**

There is a need to understand the number of adults with autism living in Lewisham in order to undertake a needs assessment and to understand service needs.

The following tables from the Institute of Public Care- PANSI, represents Lewisham’s population and future projected population by age, gender and ethnicity<sup>16</sup>. The figures are based on the ‘Autism Spectrum Disorders in Adults living in households throughout England’ a report from the Adult Psychiatric Morbidity Survey of 2007 published by the Health and Social Care Information Centre in September 2009. The prevalence rates have been applied to ONS population projections of people aged 18 to 64, to give estimated numbers predicted to have autistic spectrum disorder to 2020.

##### **People in Lewisham aged 18-64 predicted to have an Autistic Spectrum condition projected to 2020**

<b>Autistic spectrum disorders – By Age</b>	<b>2012</b>	<b>2014</b>	<b>2016</b>	<b>2018</b>	<b>2020</b>
People aged 18-24 predicted to have autistic spectrum disorders	266	260	255	250	242
People aged 25-34 predicted to have autistic spectrum disorders	568	595	613	629	639
People aged 35-44 predicted to have autistic spectrum disorders	474	502	529	554	585
People aged 45-54 predicted to have autistic spectrum disorders	368	384	397	410	413
People aged 55-64 predicted to have autistic spectrum disorders	212	222	240	264	286

Total population aged 18-64 predicted to have autistic spectrum disorders	<b>1,888</b>	<b>1,963</b>	<b>2,034</b>	<b>2,107</b>	<b>2,165</b>
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By 2020 it has been estimated that the total prevalence of adults with autism in Lewisham will be 2,165 in Lewisham. Arguably this is the tip of the iceberg as many with high functioning autism and Asperger Syndrome may not be diagnosed. Moreover, of the adults with the condition, it is not possible to estimate how many will have a formal diagnosis. A formal diagnosis may enable individuals to seek out services and help from adult/disability services.

**People aged 18-64 predicted to have autistic spectrum disorders, by age and gender, projected to 2020**

<b>ASD by gender: Males</b>	<b>2012</b>	<b>2014</b>	<b>2016</b>	<b>2018</b>	<b>2020</b>
Males aged 18-24 predicted to have autistic spectrum disorders	238	232	227	223	216
Males aged 25-34 predicted to have autistic spectrum disorders	511	536	553	567	576
Males aged 35-44 predicted to have autistic spectrum disorders	427	454	479	502	531
Males aged 45-54 predicted to have autistic spectrum disorders	329	344	356	369	373
Males aged 55-64 predicted to have autistic spectrum disorders	189	198	214	236	256
Total Males aged 18-64 predicted to have autistic spectrum disorders	1 694	1764	1829	1897	1952
<b>ASD by gender: Female</b>	<b>2012</b>	<b>2014</b>	<b>2016</b>	<b>2018</b>	<b>2021</b>
Females aged 18-24 predicted to have autistic spectrum disorders	28	28	28	27	26
Females aged 25-34 predicted to have autistic spectrum disorders	56	59	60	62	63
Females aged 35-44 predicted to have autistic spectrum disorders	47	48	50	52	54
Females aged 45-54 predicted to have autistic spectrum disorders	39	40	41	41	41
Females aged 55-64 predicted to have autistic spectrum disorders	23	24	26	28	31
Total Females aged 18-64 predicted to have autistic spectrum disorders	193	199	205	210	215

The rate among men remains higher than that among women which reflects the figures from childhood population studies.

## **4.2 Diagnosis and Referral pathways in Lewisham**

NICE guidelines suggest that for adults with possible autism, who do not have a moderate or severe learning disability, assessors should use the Autism-Spectrum Quotient. This is list of ten questions that sets out to identify key difficulties experienced in relation to the “triad of impairments” experienced by adults with autism. If the client has difficulty reading, the assessor is expected to read the question out to the client. A score above 6, or a diagnosis based on clinical judgment warrants a referral to a local diagnostic service for a comprehensive autism assessment<sup>17</sup>. This tool is being used within general practice settings.

Assessing challenging behaviour requires a functional analysis which comprises evaluations of factors that trigger or maintain the behaviour. This can be undertaken by combination of care/learning disability and other primary care services.

In Lewisham, the Autism Spectrum Diagnostic Clinic offers assessment and psychological support including Cognitive Behaviour Therapy (CBT) to adults diagnosed with autism. The clinic takes place at the South London and Maudsley’s Ladywell Unit, in Lewisham. The clinic was opened in June 2011 and is held once weekly. The service is undertaken by a consultant psychiatrist and a clinical psychologist. All referrals from the community are directed through the Community Mental Health Team (CMHT). This is done in order to rule out co-existing mental health problems in clients prior to their assessment. Direct consultant referrals can not be made and referrals are mostly received from GPs, The Burgess Autistic Trust, other psychiatrists and the CMHT. The average waiting time for an assessment is 6 weeks.

In a discussion with the Senior Clinical Psychologist at the South London and Maudsley’s diagnostic clinic, the clinician expressed that the clinics are extremely busy and had a steady stream of referrals. Most assessments focused on identifying and managing the “triad” of symptoms affecting the individual. There were discussions with carers but little communication with other services .i.e. Adult Social Services. The clinic have detailed notes about the autistic individuals following assessments, however information on education, housing and financial circumstances, are not documented in a systematic way, and written in free text. As these details are not coded, collating or auditing the data

is impossible and would require going through the entire patient record and extracting relevant data.

There was interest in looking at how such data can be recorded in future. It was also considered useful to broaden communication with other services involved in the care of adults with autism.

The following table was compiled for the diagnostic clinic’s October 2012 business meeting, and shows the number of assessments and diagnoses made in Lewisham from June 2011 to October 2012.

**Table 2: Autism Assessment carried out by the Ladywell diagnostic service from June 2011-October 2012**

NO. OF ASSESSMENTS	APPOINTMENTS TO SEE CARERS	NO. of Did Not Attend (DNA'S)	NO. OF FOLLOW-UPS SEEN TO DATE	NO. DIAGNOSED WITH ASD
34 seen (3 scheduled)	3	4	2	est.28

Source: South London and Maudsley NHS Foundation Trust Lewisham Adult ASC & ADHD Service, Lewisham Hospital-Ladywell Unit

In a 16 month period 34 to 37 autism assessments were carried out in Lewisham and a total of 28 adults were formally diagnosed with autism. The clinic also stated that nine clients are currently awaiting assessment.

**4.3 South London and Maudsley**

South London and Maudsley Mental Health Trust were approached to provide information about adults with autism in Lewisham. The information governance department gathered the data from *Insight* – The trusts information reporting tool, linked to the electronic patient records system. Tables 1-3 below indicate that there were 33 referrals for diagnoses of adult autism in Lewisham and that general practitioners made the majority of referrals.



**Table 1: Number of referrals received for the diagnosis of adult with suspected autism in the last 5 years**

Referrer	GP	Other MH Trust	Social Services	Carer	Other
<b>Total no</b>	19	2	2	1	9

**Table 3 - Gender of patients with a formal diagnosis of Autism**

Gender	No of patients
Female	3
Male	17
<b>total</b>	<b>20</b>

**Table 2: Age range - Patients with a formal ASD Diagnosis**

Age range	Total
18-22	8
23-42	6
43-57	6
<b>Grand total</b>	<b>20</b>

**Table 4: Ethnicity of patients with a formal diagnosis of Autism**

Ethnicity	Total
White	9
Black	4
Asian or Mixed	3
Not stated	4
<b>Grand Total</b>	<b>20</b>

The information provided by SLAM illustrates the expected high prevalence of autism among males, rather than females. The majority of adults were aged 18-22 and were White, closely followed by African Caribbean groups.

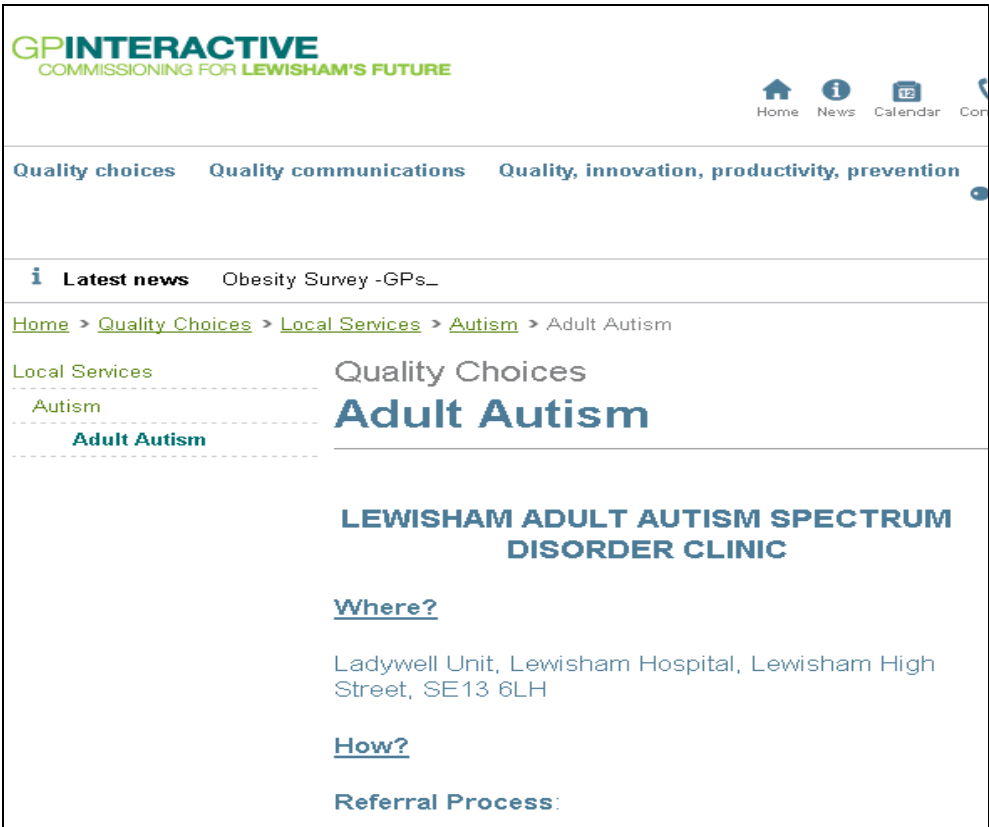
However there is a disparity between the information held by SLAM and the diagnostic services, reiterating that health and social care institutions are not correctly documenting details about adults with autism.

#### **4.4 Autism and Lewisham General Practices**

The GP interactive website is a tool that can be accessed by all GPs and practices in Lewisham. It provides access to activity data, prescribing/ performance information, quality alerts, and service information. It is a resource to support practice engagement and to facilitate effective commissioning. The site provides GPs with guidance and local referral pathways for adult autism. The Autism Spectrum Quotient (AQ-10 ),a quick referral guide for adults with suspected autism who do not have a learning disability is being developed for the website. See Figure 1.

In Lewisham 42 out of 43 general practices use the same medical information software system, known as EMIS Web, to record patient data. All conditions or diagnoses utilise Read-codes as a method of recording. Although there are no autism registers kept by GPs, the numbers of people with a known diagnosis of autism registered with a GP may be sought by auditing the codes in Figure 2. This data is not available at present but should become accessible in the near future.

**Figure 1. GP Interactive Website: Referral Pathways for Adults with Autism**



**Figure 2: EMIS WEB© Read-Codes For Adult ASD**

Diagnosis	Read-code
Autistic spectrum disorder	Eu84z-1
Autism	E140-2
Autistic disorder	Eu840-1
Suspected autism	1J9
Asperger Syndrome	Eu845
Atypical Autism	Eu841

**5. Current Activities and Services:**

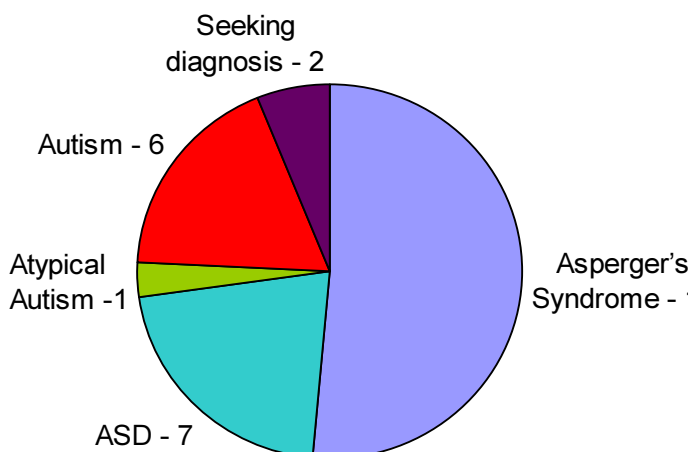
**5.1 Burgess Autistic Trust**

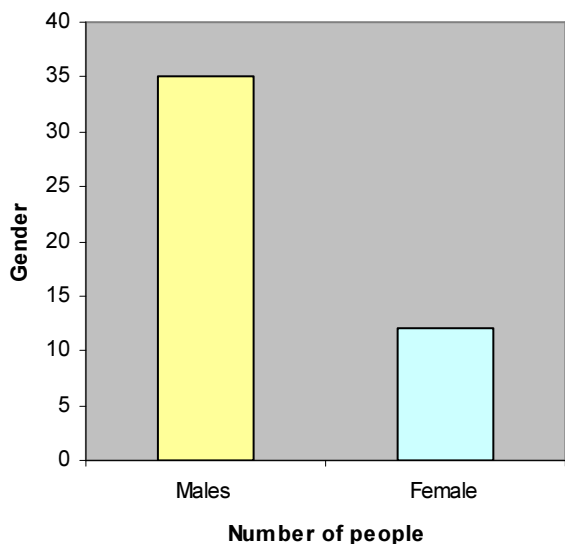
The Lewisham Joint Commissioning Unit have commissioned The Burgess Autistic Trust (BAT) a specialist independent charity to provide information, advice and support to adults with Autism in Lewisham. The service provides support to adults aged 19+ includes, help with further education, employment, social skills and peer support. Burgess Autistic Trust has an open referral system and is targeted towards those who are FACS (Fair Access to Care Services) ineligible, i.e. not eligible for social services support. Currently the Burgess Autistic Trust has 47 service users that have been referred and fully reviewed by the service. In addition there have been a further 54 independent enquiries. The following graphs 1-4 contain data collated by the Burgess Autistic Trust pertaining to the service users.

**Data for Lewisham ASD Information, Support and Advice Service**

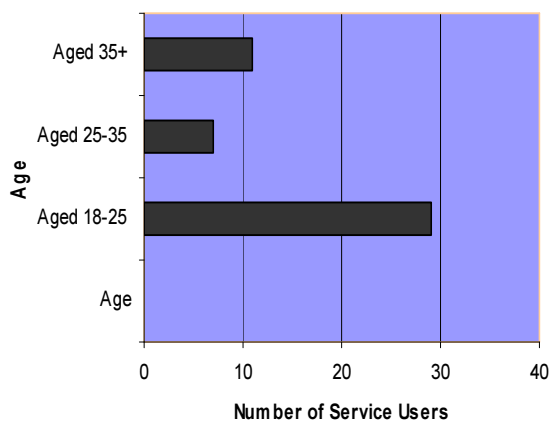
**Graph 1: Gender of Service Users**

**Graph 2: Range of Diagnoses**

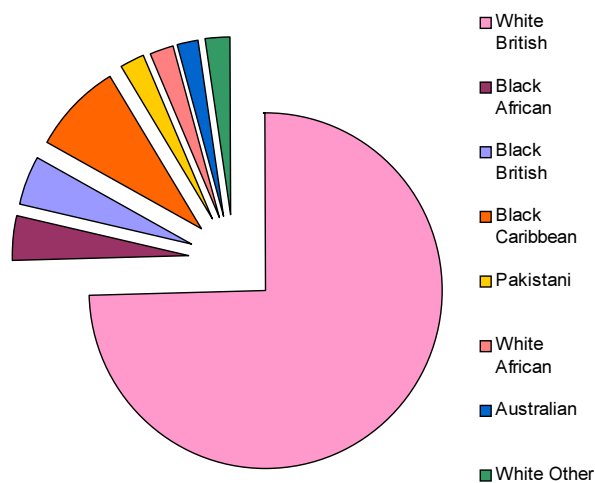




**Graph 4: Ethnic Distribution**



**Graph 3: Age Distribution**



Burgess Autistic Trust report that a large percentage of people stated that they were unhappy about their living circumstances. Thirty-two out of the fifty-four adults with autism were still living with their parents. Service users raised their concerns stating that their accommodation arrangements were as precarious as “sofa surfing” to time limited housing placements and living with friends or family.

**Figure 3: Housing status of BAT service Users**

Living circumstances	Number of People
Living independently	8
Living with family/spouse	5
Living with parents	32
Supported Living	1
Shared house	1

In all, 33 people were not in any education, employment or training and only 6 people were in employment (Figure 4). Most of the service users received employment and support allowance (ESA) and participate in work related activity groups. Over 50% of people informed BAT that they were actively seeking and wanting employment. BAT is working towards developing the employment support they presently offer ( Figure 3).

**Figure 4: Education and Employment status of BAT service users**

Education, Employment, unemployed	Number of People
NEET – Not in Education, Employment or Training	33
Employed	6
Education	7
Unknown	1

**5.2 Autism Awareness Training**

Lewisham has commissioned Autism Awareness training from Enderby Training for frontline staff working in health and social care. This was based on statutory guidance detailed in the 2009 Autism Act. The half-day training provides people with key learning about autistic people’s cognitive processing and communication difficulties. The course aims to improve professionals’ communication and understanding of the needs of autistic individuals, and how to meet their specific needs. It also highlights the importance of considering the impact that an environment can have on autistic people.

**5.3 Adult Social Services and Disability Services**

Adult Learning Disability services offer support to disabled people with a concurrent diagnosis of autism. The Learning Disability service was unable to offer any details of their autistic service users. There is no champion with specialist training in managing disabled adults with autism within the service. There was very little in the way of data – from their IAS service user electronic records system.

The SCAIT team is the first port of call for any person in Lewisham requiring social care needs assessment and support. Social workers working in the frontline recognise that assessing needs is more important than a person’s diagnosis, however social workers

stated a diagnosis of autism would open doors to more specialist services and support for people.

The SCAIT team record all data on to an electronic records system- IAS. In discussions with three frontline social workers, all three stated that there was no easy way of formally recording a diagnosis of autism on the records, owing to a lack of an appropriate drop down menu or tick box to record the diagnosis/suspected diagnosis. Any details pertaining to autism would be mentioned in the free text part of the records. Furthermore the social workers felt inexperienced in dealing with adults with autism and were not aware of the Endersby training or Burgess Autistic Trust as a newly commissioned resource for FACS ineligible Adults with autism. This demonstrates the need for improved training and better communication between different health, social care and specialist services so as to appropriately direct an autistic person to the correct services.

#### **5.4 Transition Services**

Lewisham's transition services, helps young people with disabilities or learning disabilities make the transition into adult life. The report 'Implementing fulfilling and rewarding lives' emphasises the need for transition to be planned and managed over a number of years, and for young people with autism, and their families and carers to be involved in transition planning. However, the report also highlights the need for information to be passed on between children's and adult services. This is vital not only for the long-term needs of the individual to be met, but also to share information about the numbers of children with autism in a local area and to assist longer-term service planning.

In the process of transition many may find themselves no longer eligible for the same services. However their adult status may entitle them to receive benefits and further support.

A Review of services for children and young people with autism spectrum disorder in Lewisham carried out by Public Health in 2012 highlighted that joint working between Children and Young People services and Adult services needs to be addressed urgently.

The transition team was approached for information about the numbers of young adults with autism and the support they are given however in the timescale no information was

received from this service. This information is vital in order to assess number of young adults with autism in Lewisham currently and in the future.

## **6. Assets**

### **6.1 CLASH**

The CLASH (Campaign in Lewisham for Autism Spectrum Housing) is a lobbying group representing people diagnosed with Asperger Syndrome or high functioning autism in the Lewisham community with housing needs. CLASH have worked to increase public awareness of the need for housing for adults with autism and acceptance of people with the condition within local communities. They have carried out surveys among their members to gather people's views on needs and experiences of local specialist housing provisions. The survey and other recommendations by CLASH has provided useful information to inform future commissioning and examine current housing provisions. CLASH currently has 60 members (Figure 5).

**Figure 5 : Members of CLASH by Ward in Lewisham**

Ward	No of members by their addresses / wards
Bellingham	3
Blackheath	1
Brockley	3
Catford South	3
Crofton Park	8
Downham	5
Forest Hill	3
Grove Park	4
Ladywell	3
Lee Green	5
Lewisham Central	5
New Cross	1
Perry Vale	5
Rushey Green	5
Telegraph Hill	3
Whitefoot	3
<b>TOTAL</b>	<b>60</b>

## **6.2 Support Information, Guidance News for Autism in Lewisham Family Support Limited. (SIGNAL FS Limited):**

SIGNAL FS Limited is a Lewisham based voluntary parent support group, which was set in 1993 by parents of children with autism spectrum condition and Asperger Syndrome. It is a charity that is mainly run by parent volunteers.

The charity offers support to parents of children with autism, provides up to date research and education on topics related to autism. SIGNAL are also involved in lobbying for improved educational provision, promoting better community awareness of autism and provide clubs and activity groups for children with autism<sup>20</sup>.

## **6.3 National Autistic Society.**

The National Autistic Society is the UK's largest provider of specialist autism services, providing key support to 10,000 people every year. Branches in the South East include Bexley, Greenwich, Lambeth and Southwark. Their services range from providing emotional support, education, and recreational activities for children with autism, their parents and carers, together with groups for adults with autism, their families/carers, professionals working with them and drop-in information and advice sessions<sup>21</sup>.

## **7. Local Views:**

In 2011 CLASH held discussions with the heads of strategic housing in Lewisham and agreed to carry out a survey to assess the housing needs among its members. In all, 20 members were surveyed. A total of 19 respondents were parents or carers of an individual with autism, in many cases these individuals with autism offered their experiences and views. The 20th respondent was an adult with autism.

The respondents did not have clear preferences between flats or converted houses or a specific locality for housing development in Lewisham. The respondents highlighted the need for adequate security in the properties and special consideration to lighting arrangements, to minimise sensory disturbance.

The respondents voiced the need to have trained staff in the day and for some also in the evenings to provide further support to individuals who need it. There was a preference for the residences to be in close proximity to transport, leisure and shopping infrastructure.



Further support and training in relation to managing finances, access to health care, activities of daily living i.e. cooking and self-care was deemed very important in facilitating supported/independent living<sup>22</sup>.

These issues were also reflected in the qualitative needs assessment of Lewisham adults with autism carried out in 2009. Two key concerns raised by the adults with autism was the tendency for them to become socially isolated and open to exploitation due to their social naivety. There was a need for a local service which promoted socialization, mentoring schemes and drop in services for advice and skills development.

The majority of participants reported negative experiences in regards to their early education. A combination of bullying, insensitive teachers, inappropriate schooling or home schooling undermined their progress to higher or further education. Those participants already in college state they received adequate support but that it would have been useful for the support to be in place from the very start of their education. Most participants relied heavily on their parents or the voluntary sector for support.

Lack of formal education achievement was noted to be particularly problematic for adults with 'high functioning autism' as these are the people who have more potential to complete training, which would help them achieve greater autonomy, employment and an improved quality of life.

Lewisham residents also raised concerns about conflicts at home for young adults with autism. There were incidences of violence from autistic teens requiring police intervention. There were other reports of young adults becoming withdrawn, socially isolated and over dependent on their families. This exacerbates their disengagement from the world and contributes towards crisis in later years when parents are too old to care for them.

Out of borough special residential services have been reported to be highly valuable, however there are no residential or supported housing options in Lewisham for people with higher functioning autism. Participants noted that services provided by the Learning disability services were excellent, but failed to cater to ASD related social and communication impairments, which caused decline in service users mental health.

Removing ASD adults from their families, their culture and communities required a large adjustment and raised serious concerns among families. This highlights the need for cultural and religious sensitivity in service provision.

The needs assessments detailed that Lewisham carers save services substantial money, however without support, the stresses upon a carer can result in increased need for health care services for ASD sufferers and their carers in the long run. This problem stresses the need for better dialogue between carers/families of autistic people and services, aimed at keeping up to date with local needs.

## **8. Recommendations**

Following review of the 2009 Autism Needs Analysis and talking to a number of health and social care professionals, a number of recommendations for future development have been made.

Formal documentation of an autism diagnosis, is an area that needs to be addressed by Adult Social Care and Lewisham Disability Services. Better documentation will enable the local authority to develop a better understanding of the needs of autistic people.

1. Improvement of the Integrated Adult Services – patient records systems need to incorporate a drop down box for autism, i.e. Intellectual disability (inc Autism and Asperger Syndrome).
2. Promote and provide on-going training to health and social care staff to equip them to deal with confidence with services users with autism.
3. Nominate individuals to be Autism champions in the Adults Social Care and Disability department, to raise awareness of the condition, promote training and support front line professionals/colleagues to keep up to date on available services i.e. Burgess Autistic Trust and NAS groups.
4. Implement the recommendations from the Review of services for children and young people with autism spectrum disorder in Lewisham, on transition.

*Recommendation 29: Transition between children and adult services, and in particular the current gap existing for young people with ASD without mental health or learning impairment needs to be addressed urgently by joint working between Children and Young People services and Adult services.*

5. Robust protocols to be in place ensure that people diagnosed at the Ladywell Autism Clinic are referred to the appropriate services
  
6. More communication with Lewisham Clinical Commissioning Group would be useful. A regular audit of the number of people diagnosed with Autism should be carried out. Because of the homogenous use of EMIS patient record systems among Lewisham general practices, numbers of adults with autism in general practice can be audited using the given Read codes.

## **9. Conclusion**

Autism is a group of enduring developmental disorders. Higher functioning people cope well on a day to day basis whereas others require significant support. There are substantial health and social inequalities faced by autistic people, which has led to UK's first ever disability specific act, the Autism Act 2009. National measures and guidance have been undertaken to improve autism diagnostic services, awareness and training of health and social care professionals. This in turn facilitates better commissioning of services, aligning with the views and needs of people with autism and their carers.

In Lewisham the projected estimate of the number of adults with autism in 2020 is 2167. In line with national guidance, Lewisham has taken positive steps in commissioning services for adults with autism autistic people i.e. The Burgess Autistic Trust, and training, i.e. Endersby training. However the lack of formal documentation about adults with autism who contact services in Lewisham contributes to a partial understanding of the needs of adults with autism. To enable the completion of a comprehensive JSNA topic on Adults with Autism to inform commission of services will require that these recommendations are carefully considered.

## **10. Appendices:**

Appendix 1: DSMIV criteria- TABLE

Appendix 2: CONDITIONS CO-EXISTING WITH AUTISM - TABLE

## 11. References

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