

## THE AUTISM SPECTRUM Fact Sheet

### **Background**

Autism is a lifelong developmental disability that affects the way a person communicates and relates to other people. The term Autistic Spectrum is often used because the condition varies from person to person. Classic autism (Kanner's syndrome) is associated with a low IQ and often occurs together with a learning disability. It is important to differentiate this from people with Asperger's syndrome who do not have classic autism.

Asperger's syndrome is seen primarily as a social disability, distinguished from the other Autistic Spectrum Conditions/Disorder (ASC/D) in having no general delay in language or cognitive development. People with Asperger's Syndrome have fewer problems with speaking and are often of average, or above average, intelligence. Usually they do not have the accompanying learning disabilities associated with classic autism, however they may have specific learning difficulties, include dyslexia and dyspraxia or other conditions such as Attention Deficit Hyperactivity Disorder (ADHD) and epilepsy. Although the behaviour of those who have been given the diagnosis may be unusual, a minority might need specialist health and social care services. There is wide variation in social adaptation of people with Asperger's syndrome in adolescence and adulthood.<sup>1</sup>

The safeguarding of vulnerable adults is always of paramount importance when considering people with ASC/D. Vulnerability varies on an individual basis depending on where on the spectrum the person sits and also whether they also have a learning disability. With the uncertainty of specific numbers of adults with ASC/D it is difficult to know whether all are being appropriately cared for and their best interests served.

### **Autism Act 2009**

In late 2008 Cheryl Gillan MP agreed to take forward a private member's Bill on autism in Parliament. A huge campaign effort and cross-party support in Parliament resulted in the Bill receiving Royal Assent and becoming the [Autism Act 2009](#) on the 12<sup>th</sup> November 2009.

The Act made two key provisions:

- That the Government produce an adult autism strategy by 1 April 2010
- That the Secretary of State for Health issue statutory guidance for local authorities and local health bodies on supporting the needs of adults with autism by 31 December 2010.

The *Autism Act 2009* committed the Government to publishing an adult autism strategy to transform services for adults with autism. The publication of this strategy meets this commitment.<sup>2</sup>

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<sup>1</sup> People with learning disabilities. Annual Report of the Director of Public Health 2008, Sutton and Merton Primary Care Trust

<sup>2</sup> Autism Act 2009. <http://www.legislation.gov.uk/ukpga/2009/15>

## **Sutton - The Local Picture**

Finding an exact figure of the number of adult residents of Sutton with ASC/D is difficult as many people have not been in touch with services since leaving school and some will be living full, independent lives without external agency support. From PANSI and POPPI<sup>3</sup> estimates, ASC/D prevalence is approximately one in a hundred people, and around half of these would have learning disabilities also. **Fig.1.** indicates the estimated prevalence to year 2030 in Sutton.

**Fig. 1: Predicted number of adults in Sutton to have Autistic Spectrum Disorders**

Age Band	2014	2015	2020	2025	2030
18-24	142	140	132	136	160
25-34	275	277	282	283	273
35-44	301	307	327	344	351
45-54	291	297	307	317	339
55-64	202	206	243	273	283
65-74	150	152	166	176	208
75 and over	121	121	137	170	192
Total aged 18-64	1,211	1,227	1,291	1,353	1,406
Total aged 65 and over	271	274	303	345	399
<b>Total predicted to have ASD</b>	<b>1,482</b>	<b>1,501</b>	<b>1,594</b>	<b>1,698</b>	<b>1,805</b>

Source: POPPI, PANSI

Over the past years Sutton's planning and service provision has concentrated in supporting people from the long stay learning disability hospital and many of those have an Autism Spectrum Condition/Disorder (ASC/D). Limited data exists on the actual numbers of people with ASC/D who may not have a learning disability. Therefore we are unable to quantify the needs of people with ASC/D who are not learning disabled.

## **Sutton progress**

In September 2013, the London Borough of Sutton conducted a review of its strategic position against the implementation of the National Autism Strategy 'Fulfilling and Rewarding Lives'. Two independent agencies; Ambitious about Autism and the National Development Team for Inclusion, were commissioned and facilitated the development of this work. A consultation event took place, bringing together local stakeholders to discuss what works and what needs to change to improve the lives of people with ASC/D. As a result of this work the London Borough of Sutton Autism Strategy Framework was developed.<sup>4</sup>

<sup>3</sup> Projecting Adult Needs and Service Information <http://www.pansi.org.uk/> and Projecting Older People Population Information System <http://www.poppi.org.uk/>

<sup>4</sup> Autism Strategy Framework for Sutton October 2013

## **What works**

Sutton's vision is to be an Autism 'aware and friendly' borough, where all services understand and treat those with ASC/D equally and well. The direction of travel is to take a lifelong approach to meeting the needs of people with ASC/D.

- Transition: there should be no gaps between adults and children's services which will help to a more robust and effective commissioning structure for future planning and design of services
- Engagement and involvement: the voices of people with ASC/D are integral for future commissioning and planning. Delivering on the Personalisation Agenda is seen as central to ensuring people have choice and control over the services they receive
- Occupation: how people spend their time and to ensure they are included in their communities with a particular focus on employment, including paid and unpaid work.
- Better Health: ensure that people have full and equal access to good quality healthcare for both physical and mental health needs
- Access to housing: ensure that people have options for housing that they want and need with focus on ownership and tenancies
- Planning and Leadership: make change happen and ensure that partnership boards/structures are more effective in delivery of policy

## **Links to further information**

- National Autistic Society <http://www.autism.org.uk/>
- National Autistic Society (Surrey Branch) <http://www.nassurreybranch.org/home.html>
- Autism Independent UK <http://www.autismuk.com/>
- Projecting Older People Population Information <http://www.poppi.org.uk/>
- Projecting Adult Needs and Service Information <http://www.pansi.org.uk/>
- Nice Guidelines <http://pathways.nice.org.uk/pathways/autism?fno=1>

## **Priorities for Sutton**

The Autism Strategy Framework for Sutton has provided an action plan with recommendations based on the 7 main outcomes of the Autism Strategy. This work is overseen by the Sutton Adult Autism Strategy Steering Group.

Based on the recommendations from the Autism Strategy Framework for Sutton, there are a number of priorities which future commissioning and planning need to address as follows:

- Improve the identification of people with ASC/D and build a robust data base and information register
- Develop a user engagement and involvement strategy
- Increase raising awareness and training for frontline staff and professionals
- Increase awareness of the referral, diagnostic and assessment pathway
- Scope and map local services and ensure local service provision is good enough to those in need
- Ensure local housing strategy development meet the needs of those with ASC/D with and without learning disabilities
- Help to support employment opportunities for people with ASC/D



- Support the criminal justice system, understand those with ASC/D and have reasonable adjustment in place and treat them well
- Support development of accessible and appropriate communication channel for people with ASC/D

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