

## 7. ADULTS

### 7.10 Autism

Autism is a lifelong spectrum condition, sometimes referred to as autistic spectrum disorder (ASD) or autistic spectrum condition (ASC). Autism Syndrome Condition is defined as “a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them.”<sup>i</sup>

The main areas of difficulty, which all people with autism share are social communication and interaction and restricted, repetitive patterns of behaviour, interests or activities. Autism is a spectrum condition, which means that, while all people with autism share certain difficulties, their condition will affect them in different ways and so during diagnosis the aim is to identify all the needs that someone has and how these affect their life.

Autistic behaviours are typically present in early childhood but features may not become apparent until the circumstances the child or young person change; for example when they go to nursery, or primary school or when they move to secondary school.

Asperger Syndrome is an autistic spectrum disorder where people tend to be more able and have good verbal skills and often have average or above intelligence. As with any Autistic Spectrum Condition, people with Asperger Syndrome may also have specific learning difficulties such as dyslexia and dyspraxia.

Changes to the diagnostic criteria in 2013 means that the term Asperger Syndrome, is not recognised as a separate diagnostic category.

#### *7.10.1 The impact of autism*

Autism is a lifelong condition that has a great impact on the individual, their family and carers. A diagnosis of autism can provide an understanding of why an individual is different from their peers and the types of support they may need from education, health and social care.

In the 1980s Autism was understood to be a developmental disorder with a very low prevalence. In recent years research has suggested 1% and some research as high as 1.6%. The increase in awareness and understanding is reflected in the increase demand for diagnosis.

According to research published by Emerson and Baines in 2010<sup>ii</sup> around a third of people who have learning disabilities also have autism. Conversely two thirds of

autistic people do not have a learning disability and therefore Autism Syndrome Condition should be considered independently.

Autism associated with severe learning disability may require complex and coordinated approaches to service provision across health education and social care. For those individuals with autism who are able to experience fulfilled lives and live independently, support may be required episodically at times of high stress.

A diagnostic pathway has been established for adults in Buckinghamshire. Further work is required to ensure a whole system approach and that delays to diagnosis are minimised.

Delays in diagnosis can often lead to delayed appropriate or specific interventions. This in turn leads to the development of the complications and co morbidities from the unrecognised/undiagnosed autism. In addition, delayed responses can result in an increased burden of care for families, educators and immediate communities.

Improvements in the collection of data and analysis of information about adult autism are a key concern both nationally and locally. Good and robust information informs the development of services, including training across universal services.

#### 7.10.2 Information on autism

Autism prevalence is difficult to accurately record, as there is no central register of people who have autism and the condition itself may not always be diagnosed. Estimates of the prevalence of autism spectrum conditions in adults range from 0.9% (Green et al 2005) to around 1.6% (Baron-Cohen, 2009). Generally, the estimates for the Autistic population are based on a prevalence rate of 1%, with a higher proportion of men (1.8%) affected than women (0.2%).<sup>iii</sup> Based on this estimated prevalence, there are approximately 442,000 adults in England and Wales with an autistic spectrum condition.

The following table shows the estimated number people with Autistic Syndrome Disorder, in Buckinghamshire.

**Table 1 Estimated number of people with Autistic Syndrome Disorder in Buckinghamshire**

Number of people		Prevalence of autism	Estimated numbers of people with autism in Buckinghamshire
Total Population	505,280	1.1%	5558
Age 0-19	126,320	1.1%	1390
Age 20-64	293,062	1.1%	3224
Age 65+	85,898	1.1%	945

There are no reliable estimates on the prevalence of Asperger's syndrome, however, studies suggest that around half of all those with autism also have a learning disability and the other half are likely to have high functioning autism including Asperger syndrome. This would suggest that there are around 2780 individuals with high functioning autism in Buckinghamshire.

The proportion of the population affected is similar to regional and national averages. In April 2015 an Adult Autism Diagnostic Service has been set up within the health and social care system. Where appropriate a post diagnosis service is available. Individuals diagnosed as ASD are assisted to identify services that can provide support. To date 50 people assessed, 15 patients were given a diagnosis of ASD.<sup>iv</sup>

### *7.10.3 Inequalities*

#### 7.10.3.1 Mental Health

Autism is linked to poor mental health and emotional health; approximately 65% of people diagnosed with autism also meet the criteria for at least one other psychiatric disorder, these additional psychiatric disorders can often go undiagnosed (Ghaziuddin et al, 1998). Due to the difficulties faced by people with autism in communicating feelings of disturbance, anxiety or distress, recognising and diagnosing psychiatric disorders and mental ill health in people with autism can be difficult. The diagnostic pathway for Buckinghamshire has taken this into account by aligning the diagnostic pathway with that of the mental health pathways, ensuring that underlying mental health issues are addressed.

#### 7.10.3.2 Employment

The National Autistic Society (NAS, 2013) research suggests that only 15% of people with autism are in full time employment and 66% are not working at all. Unemployment figures for Buckinghamshire are low in comparison with national rates; however, this would still indicate a figure of about 2000 working age adults not in employment.

Autism is often associated with a number of traits which could be considered attractive to employers, for example, an attention to detail, punctuality and adherence to rules. However, some individual's require a high level of support and an understanding around behaviours and environmental needs in order to secure employment.

#### 7.10.3.3 Family

A diagnosis of autism can effect families and family members differently; from relief at getting a diagnosis to anger and disbelief. The stresses on a family affected by autism can be considerable; both on individuals or significant strain on marriages/partners causing breakdown. The autism awareness report (Broach et al,

2003) showed a lone parent rate of 17% among families with an autistic child compared to 10% in the general population.

A diagnosis of autism often means a number of adjustments and many people with autism will require some level of care and support throughout their lives; often this may be carried out by family members.

#### 7.10.3.4 Housing

People on the autistic spectrum can struggle with change and with life skills, which can inhibit their ability to lead independent lives. A study in 2007 found that people with autism are more likely to be in social rented accommodation than the general population; 8% of people with autism in contrast to 4.4% of those without autism. The National Autistic Society (NAS, 2013) has found that 41% of people with autism are living at home with their families and 14% live in their own home with support.

The most severely disabled individuals with autism require around the clock care and specialised accommodation solutions, such as residential care homes. There is clear evidence that some people with autism require accommodation that is specific to their needs which may include a variety of sensory adaptations. However, with the right support and adaptations most properties can be used to meet an individuals accommodation needs.

#### *7.10.4 Demand*

The first generation of people diagnosed with autism in childhood are now reaching middle age and there are also mature adults being diagnosed for the first time. Historically Autism-specific services have tended to concentrate more on the needs of children and younger adults. The challenge we now face is how to extend that reach to older adults. Any development of services will need to take into account the changing, age-related needs of older people;

There are relatively few social groups specifically for people with autism. While there are opportunities in other areas, they may need to be somewhere where their social difficulties will be understood.

The risk associated with this is greater rates of mental health problems, which are known to influence and be influenced by social isolation and loneliness. Up to 1 in 15 people with Asperger's Syndrome experience symptoms of depression and many have anxiety.<sup>1</sup> This issue is in the process of being addressed with commencement of ASPIES groups located initially in the Aylesbury area. Groups in other localities will be set up over time.

The population of Buckinghamshire is predicated to increase by 4.5% by 2026, to about 531,400, with a relative potential increase of 20 children with autism born each year in Buckinghamshire.

The prevalence of autism is not thought to be higher in any specific ethnic group; however, as the population in Buckinghamshire increases this will need to be taken into account to ensure that support is culturally sensitive.

The prevalence of autism is much higher in males. National research (NAS, 2013) shows that 90% of people with autism are male. This will be significant when developing support and new services. In the case of estimated figures for Buckinghamshire we would expect that of the total, about 5000 individuals with autism are male.

Currently in Buckinghamshire there are insufficient appropriate housing options for adults with autism. As a consequence placements are made out of the area. The aim is to develop support and accommodation to meet an individual's needs closer to their family.

#### *7.10.5 Horizon scanning*

In Buckinghamshire the local strategy has at its core the aims and recommendations of the National Autism Strategy (Rewarding and Fulfilling Lives and subsequently Think Autism). The aim has been to develop a joint autism strategy which takes a life span approach; ensuring a continuous and clear pathway to access services and support for children through to adulthood.

There is a commitment by all stakeholders to collaborate in order take a multi agency approach across education, health and social care and make the best possible use of resources. In particular to improve and further develop the transition of young people into adulthood and broader NHS services.

Identifying and better understanding the needs of children with complex behaviours and autism, along with a scoping exercise of the current support available will help shape services for the future. Improved coordination of health education and social care and increased working with specialist providers will be the focus of further development of the strategy.

#### *7.10.6 Public views*

According to research carried out by the National Autistic Society The top three supports that [parents and carers] believe that their son or daughter would benefit from to address social isolation are, social skills training (60%), social groups (56%) and befriending (49%).<sup>v</sup>

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<sup>i</sup> Fulfilling and Rewarding Lives: the Strategy for Adults with Autism in England (DoH, 2010)

<sup>ii</sup> Emerson, E. and Baines, S. (2010) *The estimated prevalence of autism among adults with learning disabilities in England. Stockton-on-Tees*

<sup>iii</sup> Brugha, T. et al (2009) *Autism spectrum disorders in adults living in households throughout England: report from the Adult Psychiatric Morbidity Survey, 2007.*

<sup>iv</sup> Figures were correct as of Dec 2015

<sup>v</sup> National Autistic Society, "I Exist" campaign demands in England' (2008) <http://www.autism.org.uk/get-involved/campaign-for-change/uk-wide-campaigns/past-campaigns/i-exist/i-exist-campaign-in-england/i-exist-campaign-demands-in-england.aspx> Accessed 20/10/15