

## Autism: Unmet Health Needs

A paper for further investment in Bracknell Forest

### Introduction

This paper aims to evidence the degree of, and significance of, unmet needs for adults with autism. The paper takes operational data from teams supporting adults with autism in Bracknell Forest.

### Background Information

#### What is Autism/Asperger Syndrome

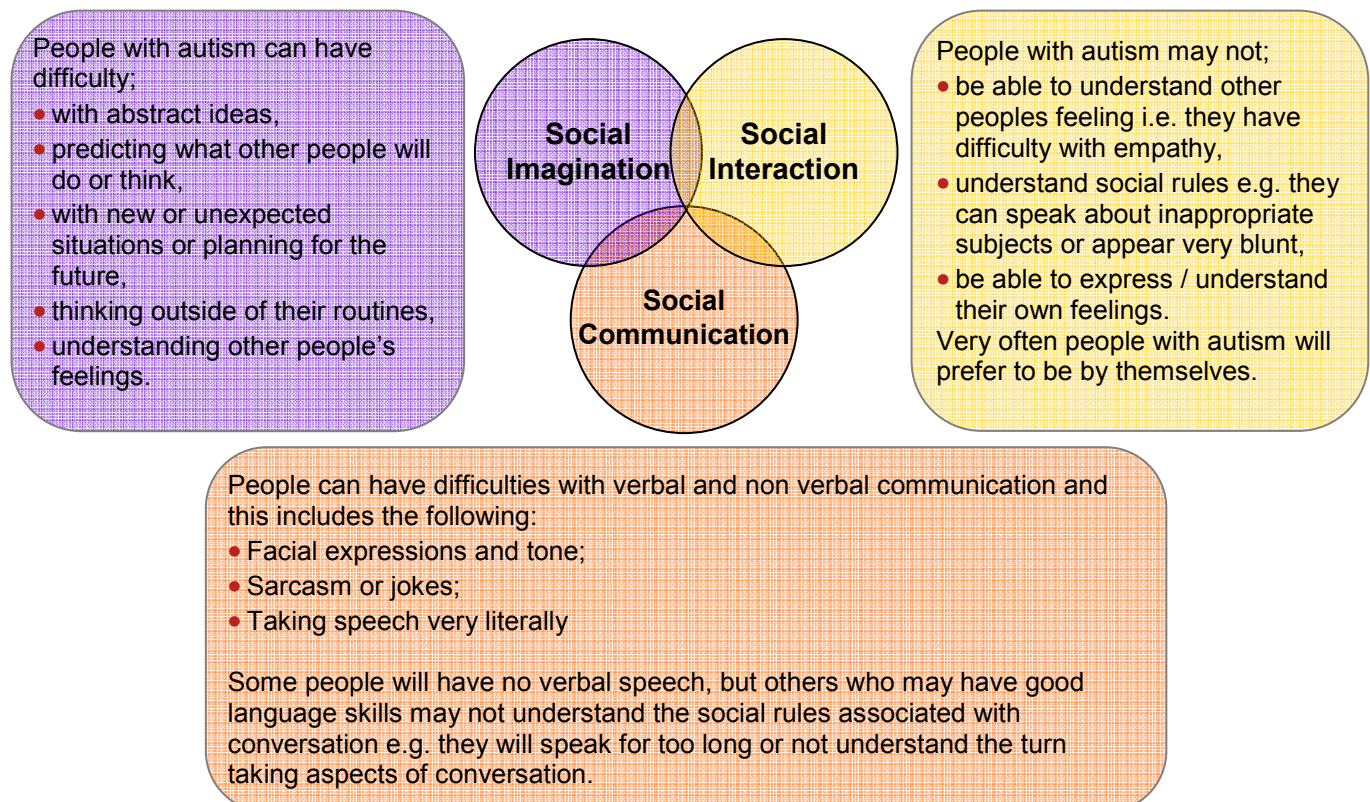
Autism is a serious and lifelong developmental disability. On its own, autism is not a learning disability or a mental health problem. However, some people with autism have an accompanying learning disability, learning difficulty or mental health problem.

Autism is a spectrum condition. This means that while all people with autism share certain difficulties, the condition affects them differently. Some people with autism are able to live relatively independent lives but others may need a lifetime of specialist support.

Asperger syndrome is a form of autism. People with Asperger syndrome are often of average or above average intelligence. They have fewer problems with speech but may still have difficulties with understanding and processing language.

People who have autism usually experience three main areas of difficulty but to differing degrees. These are called the Triad of Impairments.

#### The Triad of Impairments



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Further to the Triad of Impairments there are three other common themes to autism.

- **Routines and special interests**

*Routines:* People on the autistic spectrum can stick to their routines very inflexibly, but this may help them make sense of a world that can otherwise be very unpredictable.

*Special Interests:* Some people can develop almost obsessional interests, and they will be very knowledgeable in these areas e.g. bird watching or Dr Who.

- **Sensory sensitivity**

This is sometimes called the fourth impairment and we are now becoming much more aware of its significance.

People on the spectrum may experience over sensitivity (hypersensitivity) or under sensitivity (hypo-sensitive) in relation to any of the 7 senses; vision, hearing, taste, smell, touch, proprioception (body awareness) and vestibular (movement awareness).

*Examples of hypersensitivity:* People can find it impossible to block out background noise, deal with bright colours or the seams on their clothing.

*Examples of hypo-sensitivity:* Some people will rock or poke their eyes in order to create a sensation. Difficulties with proprioception can lead to problems in navigating rooms full of obstacles, such as furniture and people, and with fine motor skills.

- **Mental health**

People with autism or Asperger syndrome are particularly vulnerable to mental health problems such as anxiety and depression, especially in late adolescence and early adult life (Tantam & Prestwood, 1999). Ghaziuddin et al (1998) found that 65% of their sample of patients with Asperger syndrome presented with symptoms of psychiatric disorder.

Because people with autism can struggle to communicate it can mean that it is not until the illness is well developed that it is recognised. This delay in diagnosis and treatment can lead to aggression, paranoia, substance misuse, withdrawal or refusal to leave a house or room, increased obsessional behaviour and suicidal feelings.

The three main issues are depression, anxiety and obsessive compulsive disorder.

*Depression:* About 1 in 15 people with Asperger syndrome experience symptoms (Tantam, 1991).

*Anxiety:* Muris et al (1998) found that 84.1% of people with pervasive developmental disorder met the full criteria of at least one anxiety disorder (phobia, panic disorder, separation anxiety disorder, avoidant disorder, overanxious disorder, obsessive compulsive disorder). This does not necessarily go away as the child grows older. For some people, it is the treatment of their anxiety disorder that leads to a diagnosis of Asperger syndrome.

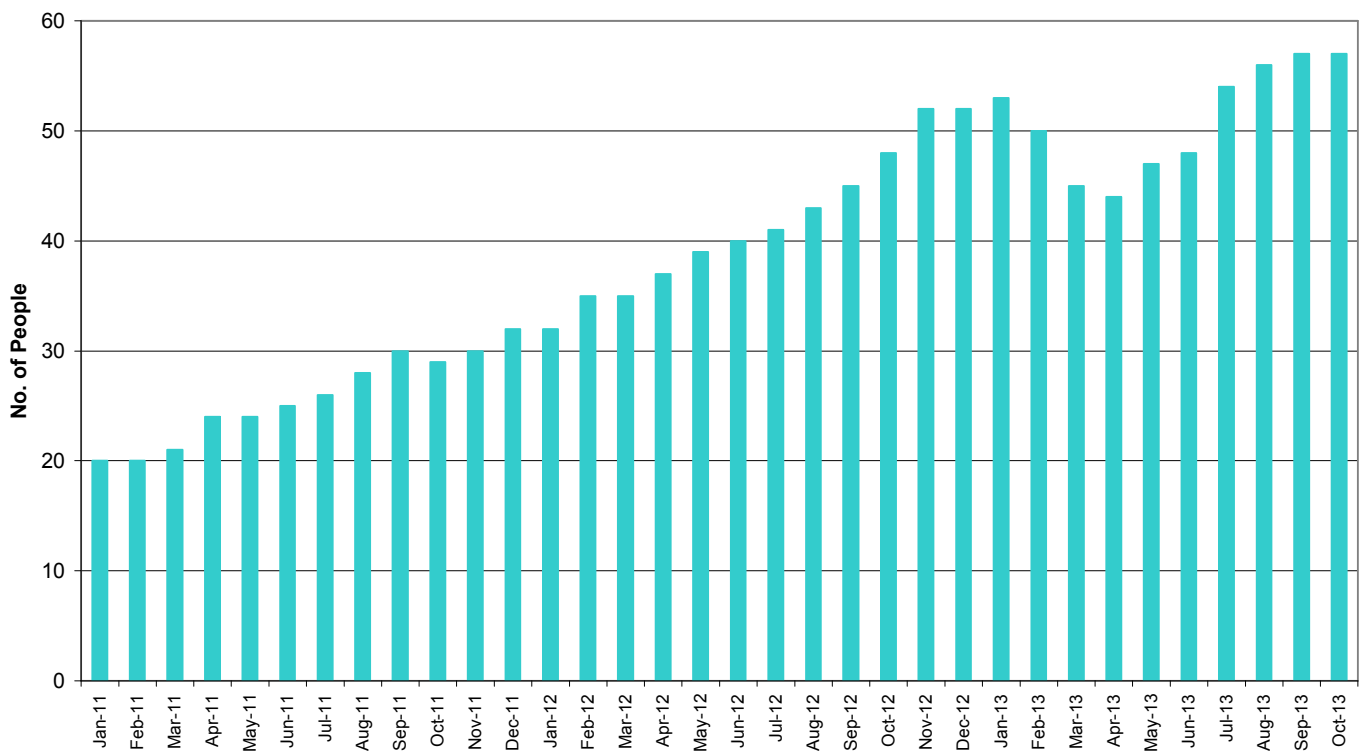
*Obsessive compulsive disorder (OCD):* Szatmari et al (1989) studied a group of 24 people to discover that 8% with Asperger syndrome and 10% with high-functioning autism were diagnosed with OCD. This compared to 5% of the control group of people without autism but with social problems. Thomsen et al (1994) found that in the people he studied, the OCD continued throughout adulthood.

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### Current Demand and Unmet Need

Below is a picture of the current demand for social services in Bracknell Forest.



Area	Demand
Adults with a diagnosis eligible for support	56
Total Population <sup>1</sup>	115,100
Population with autism (1% prevalence)	1,151

### Local Issues / Unmet Needs - The Evidence

1. Social isolation
2. Poor daily living skills and self care
3. The prevalence of Anxiety/Self harm/Aggressive behaviour/Mental health Issues

#### 1. Social isolation

Without exception, each and every individual who receives a service from the ASD team suffers a degree of social isolation and the team has used a number of strategies to alleviate this. Each case is slightly different and each requires its own strategy. Some have been more successful than others.

#### Examples:

MB is a young man who lived with his mother and two younger siblings. He rarely emerged from his bedroom. When he did it was often to verbally or physically attack his mother or sister.

CS was another young man who lived with his father and stepmother. He hadn't left their one bedroom flat for 2 years. He also had violent fantasies associated with serial killing.

<sup>1</sup> Source: ONS June 2012 mid-year population estimates

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SK is a woman in her thirties, on the autistic spectrum. She takes communication very literally and has very poor theory of mind. This is in spite of having a high IQ. As a result, she continually gets involved in a series of confrontations with her neighbours and others including the council and the health service.

In all 3 examples Psychology intervention would have helped each person to develop the necessary strategies to manage their mental health and wellbeing. However this was not available.

### 2. Daily Living Skills and self care

Many individuals struggle with this area of daily life. They are often poorly motivated and have difficulty in sequencing tasks. There are also sensory issues.

#### Examples:

SB cannot bear to Hoover because of his hypersensitivity to noise, yet he is completely obsessed by recycling to the detriment of his flat mates, and completely lacks empathy toward them. This is a complex situation which gives rise to huge difficulties for SB, and his housemates. There is no specialist health input to support him.

OT could provide a sensory assessment which would identify areas of sensory difficulty for this individual. They would then identify strategies for minimising the impact on him and those with whom he lives.

NR's flat was in such a state that the council would not enter to refurbish his bathroom and kitchen. His heating had also broken down several years before and he had gone through several harsh winters with no heating at all. He couldn't clean his flat or ask for help.

If OT support was available they would complete an assessment of his activities of daily living [ADL]. In this instance an assessment of his Domestic ADL skills would be appropriate. This would involve interview and observations of how he managed ADL tasks. Then with him the OT would develop a programme or plan to address the areas of deficit and either work directly with the individual or work with a provider commissioned to support the individual. This could be reviewed and developed as the need arose e.g. as his skills improved. Assistive technology could be used to help him with these tasks e.g. computer programmes to scaffold decision making or systems of reminders and prompts through apps on an iPhone.

SS is an example of a young lady who can hold down an office job but cannot make a snack. Again this would require a Domestic ADL assessment by an OT. A programme devised to support the person with cooking skills. This would take into account problematic areas such as sequencing the tasks within food preparation, examining reasons for possibly anxiety when cooking, looking at possible sensory reasons for a reluctance to cook (heat, texture, taste). Support would be provided through appropriate interventions such as ensuring that the kitchen and kitchen equipment/appliances were appropriate for the individual and structures to assist within the tasks visual timetables, 'easy read' recipes.

JP holds down a job but can't do up his shoe laces or use the toilet properly.

In this case the OT would use a Personal assessment ADL [PADL] looking at his self care skills. This would be in order to identify issues and devise an appropriate support plan e.g. task development tying laces, cleaning himself after using the toilet which he could work on directly or work with a support provider. They may also identify equipment that may support the individual to achieve their goals e.g. shoes with Velcro, clos-omat toilet. Advice regarding possible medical issues would also need to be sought e.g. some form of digestive disorder which may need support through dietetics service.

As with other people referred to OT the role of the OT is to assess and evaluate an individual's skills and abilities through ADL and develop interventions, treatments and programmes to overcome any

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difficulties. As with any OT interventions the person is placed at the centre of both the assessment and intervention process<sup>2</sup>. The aim is to work with him/her to achieve his/her goals.

The role of Occupational Therapy with adults with autism would have two main features:

### 1. Activities of Daily Living

This could involve the full spectrum of activities within an individual's life from self-care, domestic, accessing the community, leisure and employment, depending on the individual's need. Programmes based on assessment would be devised. OT could provide direct support for individuals or work with provider agencies to set up programmes that will improve daily living skills and self care e.g. through individualised programmes based on task analysis, through using appropriate equipment and assistive technology. Interventions could range from one to one work to use of group work e.g. to develop social skills.

### 2. Sensory Assessment

Sensory problems are prevalent amongst individuals on the ASD spectrum. It is certain that the individuals supported by the team are detrimentally affected in this way. However, none of them has had an assessment. An assessment to identify issues and then strategies to deal with them could make for an immediate improvement in health and well being.

### 3. **Anxiety/Self harm/Aggressive behaviour/Mental health Issues**

#### **Examples:**

CS has been mentioned previously. He didn't leave his room for 2 years and was becoming increasingly obsessed with on line sites dedicated to mass murder. He was not sectionable and not eligible for a service from CMHT as he was not assessed as having a severe and enduring mental illness at that time. CMHT professionals gave advice in their own time. As a result Excel/Choice were commissioned and he was treated by their Psychology/Psychiatry service in a residential unit until he had recovered sufficiently to move into his own home,

The psychologists monitored behaviour and also developed strategies to help manage anxiety, social dysfunction and to improve self esteem. Psychiatry addressed CS's mental health issues and prescribed anti depressant medication which was pivotal in his recovery.

If Adult Social Care hadn't funded this package, CS was deteriorating so rapidly that he may have gone into crisis eventually needing an acute admission.

SG suffers with anxiety and poor self esteem. She is currently self harming but was told by the GP that there are no therapeutic interventions to help her.

SR is a young man who is intellectually capable of going to university and yet he cannot function without his teddy bear which he takes everywhere. The Teddy bear serves as a means of Managing SR's anxiety and without it he cannot leave the house. If he attends an activity where he cannot take the bear then his mother has to sit outside of the venue with the bear in her car so he at least knows it is somewhere near.

SR needs support to manage his anxiety in a way which does not leave him open to aggression and social exclusion. At the moment this is not available to him.

SD is now having problems with the police. The only intervention he was offered was Talking Therapies which didn't work for him, Talking therapy is a tiered time limited service that largely focuses on Cognitive Behavioural Therapy (CBT)<sup>3</sup>. However, this focuses on exploring the way individuals think about themselves and their feelings which would be very problematic for individuals who have difficulties with Social Imagination, one of the Triad of impairments. People with Autism can have difficulties in

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<sup>3</sup> CBT is a talking therapy that can help you manage your problems by changing the way you think and behave.

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dealing with abstract concepts such as feelings, they may require concrete ways of looking at emotions or may use language that is not conventionally understood. CBT can be adapted for use by people on the Autistic spectrum but this takes expertise and a good knowledge of the condition. Workers providing the therapy don't usually have this level of knowledge. As a result Talking Therapies is not usually helpful for those on the Autistic Spectrum. Because of this, SDs family paid for counselling privately.

Talking therapies also didn't work for MS who fantasises about killing her mother.

This lack of support and intervention is already having a detrimental affect on these young peoples' lives and they may well deteriorate as they get older.

In addition to Occupational Therapy skills there is a need for psychology treatments. A primary psychological treatment for mood disorder is Cognitive Behavioural therapy as it changes the way a person thinks and responds to feelings like anxiety.

According to Hare and Paine (1997) there are ways of adapting this for the use of people on the autistic spectrum but this would require the therapist to have a knowledge and understanding of autistic spectrum disorder in a counselling setting.

Psychologists are also needed to support a holistic assessment of an individuals needs as part of a multidisciplinary team set up to deliver a package of health and social care provision and then to review and evaluate that package.

They could include:

- Counselling
- Visual timetables
- Use of Diaries
- Social Scripts
- Cartoon communications
- Concrete strategies for dealing with anxiety. For example someone with little insight or imagination will have difficulty in recognising they are anxious. There they would be told that if they begin sweating and their hearts race they need to use the breathing exercises to make these symptoms diminish.

People on the Autistic Spectrum can experience a range of mental health difficulties, especially anxiety and depression. This can be mistaken for psychotic disorders so it is important that psychiatrists treating them have knowledge of autism and Aspergers syndrome.

With this expertise they can use conventional drug therapies to treat anxiety, depression and other disorders. Behavioural approaches may also be effective but any package must be tailor made and overseen by a qualified professional.

If diagnoses and interventions are made early and effectively by psychiatrists experienced in autism, then there is more likelihood that they can continue to live and be treated in their communities, thereby avoiding crises and acute admissions.

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### Demand Summary

Support Type	Unmet Need*
Adults requiring Occupational Therapy Support	15
Adults requiring Psychology Support	24
Adults requiring Psychiatry Support	5

*\*As of September 2013*

### Key Challenges

- How to secure formalised and permanent input from certain Health skill sets proportionate to need and demand. Individuals can be completely debilitated without such – see CS case study.
- Access to specialist services would certainly impact on crisis interventions but would also add a strong preventative focus.
- Over the next 10 years it is expected there will be an increase in the population of Bracknell Forest and Berkshire and therefore an increase in the numbers of people with ASD. Following national and local campaigns to raise awareness about ASD and diagnosis we can anticipate an increase in demand for assessment, support and funding.