

## **Adult Services Scrutiny Committee**

### **Tuesday, 27 April 2010**

### **Services for Adults on the Autistic Spectrum**

#### **Introduction**

The Governments' strategy for people with autism, '*Fulfilling and rewarding lives*', published in March 2010, defines autism as *a lifelong condition that affects how a person communicates with, and relates to, other people. It also affects how a person makes sense of the world around them. The three main areas of difficulty, which all people with autism share, are known as the 'triad of impairments'. They are difficulties with:*

- *social communication (e.g. problems using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice)*
- *social interaction (e.g. problems in recognising and understanding other people's feelings and managing their own)*
- *social imagination (e.g. problems in understanding and predicting other people's intentions and behaviour and imagining situations outside their own routine).*

*Many people with autism may experience some form of sensory sensitivity or under-sensitivity, for example to sounds, touch, tastes, smells, light or colours.*

*People with autism often prefer to have a fixed routine and can find change incredibly difficult to cope with. Many people with autism may also have other conditions such as attention deficit hyperactivity disorder (ADHD), a learning disability or dyspraxia. Autism is known as a spectrum condition, both because of the range of difficulties that affect adults with autism, and the way that these present in different people. For example, Asperger syndrome is a form of autism. People with Asperger syndrome typically have fewer problems with speaking than others on the autism spectrum, but they do still have significant difficulties with communication that can be masked by their ability to speak fluently. They are also often of average or above average intelligence.*

Across the country, around half of all people who have autism also have a learning disability (IQ below 70) and receive support and services from learning disability teams. However, those who have average or above average IQ (Asperger syndrome or high functioning autism) often find it difficult to access support or understanding of their needs. It is this group of people whose needs are the particular focus of the Government's Autism Bill and Autism Strategy, and to whom the work described in this paper relates.

Increasingly, support in areas such as accessing employment, developing social skills and networks, supporting carers, enabling access to housing and housing-related support, obtaining diagnosis, and maintaining health have emerged as key areas of need. Providing timely support in many of these areas can enable people to develop a greater level of independence and wellbeing for the rest of their lives.

People with Asperger syndrome have a higher incidence of mental health problems than the general population. These problems have been dealt with via normal mental health service routes, but there is considerable evidence that they may not best meet their needs, and that some of the intrinsic issues of AS may be confused with mental health problems and not be properly treated. There is also the issue that if they are 'fortunate' enough to not have low IQ (and so be picked up by Learning Disability services) or to develop a specific diagnosable mental illness, there are few services for adults with AS. Tailored services would potentially ease the issues of people with AS, as well as prevent specific mental health problems from arising, and deal with them more suitably when and if they do.

### **National context**

In recent years the Government has begun to issue specific guidance in relation to people with autism:

- **2006**
  - Better Services for People with Autistic Spectrum Disorder' published.
  - Letter to Directors of Social Services raising the profile of this group.
- **2009**
  - Consultation on the future strategy for Adults with Autistic Spectrum Condition – 'A Better Future'
  - The 'Autism Act' was passed which sets out a timetable for the publication of statutory guidance for Local Authorities regarding services for adults on the autistic spectrum. Publication is due in December 2010 and will compel Local Authorities to take into account the needs of this group when planning services.
  - DH published "Service for adults with autistic spectrum conditions (ASC) – good practice advice for primary care trust and local authority commissioners",
- **March 2010**
  - 'Strategy for adults with autism in England' published as required by the Autism Act, 2009.
- **31<sup>st</sup> December, 2010**
  - Statutory Guidance for Local Authorities and the NHS on the implementation of its Autism Strategy to be published.
- **2013**
  - The Strategy will be formally reviewed

For the first three years, the Autism Strategy focuses on:

- Increasing awareness and understanding of autism among frontline professionals

- Developing a clear, consistent pathway for diagnosis in every area, which is followed by the offer of a personalised needs assessment
- Improving access for adults with autism to the services and support they need to live independently within the community
- Helping adults with autism into work, and
- Enabling local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities

## **Local Context**

About half of people who have autism also have a learning disability. This group of people receive support from learning disability services which are commissioned by the Council through a pooled budget and lead commissioning arrangement on behalf of both the PCT and the Council. People with Asperger syndrome or Higher Functioning Autism have an IQ in the normal range or above and so do not meet the criteria for learning disability services. Historically, people with Asperger syndrome have not had a clear route to assessment, diagnosis or support and have often fallen between mental health and learning disability teams. In Oxfordshire there has been a growing interest in the needs of this group of people. Parents of people with Asperger syndrome have campaigned for action from the statutory sector. Locally there are no dedicated services for people with Asperger syndrome or high functioning autism although a number of people with the diagnosis of Asperger Syndrome are the users of mental health or learning disability services, or access the Council's supported employment service.

## **Prevalence levels**

It is difficult to quantify the number of adults with autism, and even more so the number of adults with AS/HFA. There is a lack of data on prevalence rates due to difficulties caused by variable identification rates and lack of accurate record-keeping.

Recent estimates suggest that there are around 500,000 people with autism in England, of whom around 400,000 are adults, and that autism is three to four times more common in men than women (NAO, 2009). This equates roughly to 1 person in 100 being on the autism spectrum (Uk Gov, 2008; NAS website, 2010). In Oxfordshire, this would suggest there are in the region of 5,000 autistic adults of whom at least 2,500 have Asperger syndrome or high functioning autism. Estimates from Autism Family Support in Oxfordshire suggest this figure could be as high as 3,900 people.

The following excerpt from the website of the National Autistic Society sums up the position:

*“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. It is likely that over 50% of those with ASD have an IQ in the average to high range, and a proportion of these will*

*be very able intellectually. Some very able people with ASD may never come to the attention of services as having special needs, because they have learned strategies to overcome any difficulties with communication and social interaction and found fulfilling employment that suits their particular talents. 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.”*

### **Outline of needs analysis**

Oxfordshire PCT and Oxfordshire County Council have been working together in the past year to gather information about the needs of people with Asperger syndrome or HFA in Oxfordshire and to develop a strategy for consultation. This work has built on research initiated by OBMH to collate data.

We are working with the parent of a young man with Asperger’s syndrome, who is acting as a consultant and qualified expert by experience, to carry out this work. A steering group has been established which includes senior OCC, PCT, OBMH and Ridgeway Partnership staff. Practical assistance is also being given by the National Autistic Society, Autism Family Support, a voluntary sector autism-specific service provider to children and young people and their families. The pooled budget managers from the mental health and learning disability pools are both involved.

We have conducted a range of ‘desktop’ research into the national and international research, a number of very well attended focus groups for ‘Aspies’ and their parents or carers, and discussed the issues with a range of statutory and voluntary sector representatives who provide support and help to people, as well as collating statistical information about services and people in need. The project milestones are as below.

<b>Month</b>	<b>Event/Task</b>
November 2009	Agree PID/Brief
December 2009	Establish project Steering Group Scope work for next 3 months Gain approval from Steering Group
January 2010	Arrange focus groups Mail out to providers Commence literature search Gain information from LD team via A Nursey

February 2010	Conduct focus groups Correlate responses from providers
March 2010	Conduct focus groups Complete draft literature search Complete correlation of OBMH information
April 2010	Compile information from focus groups Bring together all research strands Submit draft report
May 2010	Submit draft report
June 2010	Finalise report

The report will incorporate recommendations from the Autism Act 2009 and our research as to what type of services should be provided for this client group. Such service provision is likely to involve a re-shaping of other services (Mental Health and Learning Disabilities) as there is currently no allocated new funding for Aspergers/autism services. Consultation on the proposals will take place from the summer onwards.

### **Costs to the system**

In totality, these are difficult to fully ascertain, as is the degree to which they are preventable once better, more directed services are provided. According to the 2009 NAO report, “supporting people with adults with autism through adulthood”, there is a greater than 99% chance that providing a specialist service for adults with AS/HFA will save £67 million to the public purse once it is established and if 8% of adults with AS/HFA are identified by the service. If 14% are identified, the savings to the public purse could be £159 million. However, it is very important to understand that not all of these savings would be realised within health and social care – many of them relate to costs that would be saved on employment benefits, in the criminal justice system and elsewhere.

### **Emerging trends/information**

Five themes have been identified by previous research undertaken by the National Autistic Society, the National Audit Office and other organisations, and the questions used in Oxfordshire’s Consultation were based around these themes:

1. Diagnosis and Support
2. Help in the Community
3. Employment and Other Meaningful Activity
4. Housing and Support
5. Health

In Oxfordshire, at six Focus Groups for adults with Asperger's syndrome/High Functioning autism across the county in February 2010, data was collected from 134 people around the five themes and this is currently being collated. It is likely that the results will be similar to the findings of the NAS research report 'I exist' (2008) - which were supported by the NAO report 'Supporting people with autism through adulthood' (2009). Namely, that adults with autism are isolated, unable to access support and are dependent on their families:

- 63% of adults with autism do not have enough support to meet their needs
- 92% of parents are either very worried or quite worried about their son or daughter's future when they are no longer able to support them
- 60% of parents say that a lack of support has resulted in their son or daughter having higher support needs in the longer term
- 33% of adults with autism have experienced severe mental health difficulties because of a lack of support
- Only 15% are in full time employment
- 66% are not working at all (including voluntary employment)

### **Potential service models**

Service models specific to adults with AS/HFA are still in their infancy in England, with one of the best established services, the Liverpool Asperger Team, having begun in 2003. Gloucester, Windsor and Maidenhead and Edinburgh have also developed teams. Although they vary in size and make up, common features are multi-disciplinary team work and staff with specialised expertise in autism.

#### **Liverpool Asperger Team**

- 2001 steering group formalised; 2003 recruitment
- Established 5 years, seen some 500 people, evaluating at present (in 2009)
- Joint funding – Central Liverpool PCT & the Local Authority
- Staff:
  - Team Manager (Speech & Language Therapist)
  - Administrator
  - 2 x Community Nurse
  - Social Worker
  - Clinical Psychologist
  - 2 x Support Worker
  - Psychologist
  - Consultant Psychiatrist (1 session per week)
  - Registrars on elective placement
  - Trainee Psychologists

#### **Offering:**

- Assessment & Diagnosis
- Person Centred Approach

## AS6

- Specialist knowledge, information & advice
- Awareness training
- Clinical Interventions

### Gloucestershire

- Joint funded post Autism Co-ordinator by NAS & Gloscc CC
- An identified Team for AS services to sit within – Physical Disability
- Training – Social Workers to have basic awareness training plus 2 from each team have further training – being done by NAS

### Windsor & Maidenhead

- Community Team, LD services funded £10,000 research post.
- New Service – 10 months old (in 2009):
  - 3 staff: 1 funded by LD, 1 by MH, 1 new post, 1 more being recruited
  - Covers whole autism spectrum
  - Service overloaded already – need 8 staff for current workload
  - 1/6<sup>th</sup> size of Oxfordshire

### Edinburgh:

- One stop shop HFA/AS 16+
- Criteria includes – prevention of need for critical intervention
- Service provided by Autism Initiatives UK
- Medical professionals use building for appointments & group work
- Staff:
  - Employment/training co-ordinator
  - Outreach worker – support in own homes & community
  - Volunteer Co-ordinator – befriending, support at social groups & drop in centre
  - Sessional worker
  - Administrator

Work to identify future commissioning options in Oxfordshire will continue through the established group which draws together the PCT, Council, mental health and learning disability services, voluntary organisations, people with Asperger's syndrome and their families. Proposals will be costed and consulted on widely during 2010-11.

### Issues for discussion

- Potential cost to social and health care of currently hidden demand, rising expectations
- Training is a key strand of the Government's strategy and this also includes awareness raising across a wide range of professions and the general public. Are there innovative ways the Council and NHS might be able to take this forward with limited resources?

- Savings are realised much more widely than health and social care but investment is likely to fall largely on health and social care. The national strategy suggests the establishment of partnership boards – how might we best engage the full range of partners in this?