

## **ADULT SERVICES SCRUTINY COMMITTEE**

**TUESDAY 8 MARCH 2011**

### **Update report on Developing Services for Adults on the Autistic Spectrum**

#### **1. Introduction**

This paper provides a progress update for the Adult Services Scrutiny Committee following the last report presented on 24 April 2010.

Since April last year progress on the plan to improve local services for adults on the autistic spectrum (AS) has been informed by a detailed needs analysis and stakeholder consultation and the latest guidance described in the Statutory Guidance on the National Autism Strategy. Listed below are the developments and actions that have taken place:

- October 2010 - Publication of the Oxfordshire AS Needs Assessment report
- 10 December 2010 - A multi stakeholder AS workshop event as part of the consultation process.
- 17 December 2010 - Publication of Statutory guidance on the National Autism Strategy
- 14 January 2011 – Publication of Oxfordshire Aspergers Syndrome (AS) consultation report.
- February 2011 – Service Specifications written and proposals for service development priorities agreed to commence by 31 March 2011.
- February 2011 – Commenced scoping a strategic approach which spans the whole autism spectrum across adults and children.

The work carried out to date provides a good example of collaboration between agencies and families with realistic expectations around delivering an integrated pathway and services with limited resources.

#### **2. Summary of National guidance**

The following provides an up to date position of the national strategy guidance:

##### **2.1 The Autism Act, 2009:**

- Sets out dates for the publication of guidance for local authorities about the planning and provision of services for adults on the autistic spectrum
- Requires a plan for meeting the needs of adults with autistic spectrum conditions in England by improving the provision of relevant services to such adults by local authorities and NHS bodies

##### **2.2 The National Strategy for adults with autism in England, 'Fulfilling and rewarding lives', March 2010.**

Strategic aims for achieving improvements to:

- increase awareness and understanding of autism among frontline professionals
- develop a clear, consistent pathway for diagnosis in every area, which is followed by the offer of a personalised needs AS assessment
- improve access for adults with autism to the services and support they need to live independently within the community

- help adults with autism into work
- enable local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities

This national strategy will be reviewed in 2013.

### **2.3 The Statutory guidance for local authorities and the NHS on the National Autism Strategy, December 2010.**

The guidance requires that local authorities and the NHS seek to improve services so that:

Adults with autism, their families and carers can expect:

- staff working in health and social care have had some autism awareness training
- staff in roles which have a direct impact on access to services for adults with autism – such as GPs, community care assessors and commissioners/service planners – have received specialist autism training
- staff working in health and social care are able to identify potential signs of autism and understand how to make reasonable adjustments in their behaviour, communication and services for adults with autism
- their local authority has a named lead professional responsible for the development of diagnostic and assessment services for adults with autism in their area
- there is a clear pathway to diagnosis in their local area
- if an adult is diagnosed with autism, they will be offered a community care assessment, regardless of their IQ, and their carers will be informed of their right to a carer's assessment
- if an adult is diagnosed with autism, they will be given access to information about autism and details of potential sources of support such as local voluntary groups and national representative groups
- there is a local commissioning plan for services for adults with autism, based on locally gathered data about the numbers and needs of adults with autism in the area
- the views of adults with autism and their carers are taken into account in the development of services locally
- if they need care services, they will be able to make choices about the services they receive, and are able to use a personal budget to pay for the services they want (if they are eligible for a personal budget)
- no decision about them is made without them.

In addition, young people with autism can expect that:

- they will receive transition support as they move from into adulthood they and their parents/carers will be informed of their right to a community care
- they and their parents will be informed of their right to a community care assessment for adult services, and their carers will be informed of their right to a carer's assessment
- they are involved in transition planning and support and that no decision about them is made without them.

### **3. Summary of Local Needs Assessment and Consultation**

In December 2009 a multi agency project steering group, which includes service user and carer representation, was established and continues to operate effectively. It's remit is to harness strategic direction locally and identify the care pathway and specific service gaps, particularly for those people with autism without a LD, who are at increased risk of developing MH problems. The steering group and joint commissioning responsibility for the county is led by Fenella Trevillion, NHS Oxfordshire, lead for Asperger's syndrome and high functioning autism and Ann Nursey, Oxfordshire County Council, lead for Autism and Learning disability.

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During 2010/11 a small resource of £50,000 was identified and approved by the PCT Mental Health pooled budget to take forward work to improve the care pathway. It has been agreed to continue investment of £95,000 through 2011/12 and 2012/13. It was recognised the limited resources would not meet all the anticipated need but would have to be prioritised to provide good quality outcomes that are value for money.

All the documents referenced in the rest of section 3 below can be found at the following link:

<https://consult.oxfordshirepct.nhs.uk/consult.ti/ASneeds/listdocuments>

### **3.1 Aspergers syndrome (AS) Needs Assessment October 2010**

As part of the consultation for the Better Mental Health in Oxfordshire (BMHO) strategy, the need for more services for people with AS was identified.

In Oxfordshire a lack of information was found on how many people with AS there are, and the gap between estimated national numbers of people and current service provision is wide. Estimates on prevalence are listed below:

- about 500,000 people with autism in England
- around 400,000 are adults
- autism is 3 to 4 times more common in men than women
- roughly 1 person in 100 is on the autism spectrum
- in Oxfordshire there are about 5,000 autistic adults
- there is estimated to be 4,000 people with AS aged 14 and above in Oxfordshire, based on families known to Autism Family Support

The framework of the needs analysis undertaken in Oxfordshire formed five themes which had been identified by work undertaken by the National Autistic Society and the National Audit Office:

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

The needs analysis looked at two strands of work; the current provision, which was identified through a survey of local providers, and focus group work with service users people with AS and families and carers. The analysis highlighted both the lack of AS-specific services in Oxfordshire and the need for such services.

The key findings of the needs assessment were:

#### *Survey of services*

1. There is a lack of AS-specific adult services in Oxfordshire
2. Provision is patchy across the county
3. There is a need for training and awareness amongst mainstream school staff
4. Oxfordshire has a highly skilled hub of AS expertise within the education Service for Autism.
5. This expertise is spreading to some further education colleges.
6. Some young people with AS are able to access some social support (directly or indirectly) from CYP&F children with disabilities services.
7. Once young people with AS leave education or become 18 years old, there is very little support for them
8. There are some professionals knowledgeable in AS amongst all of the services, but this has more to do with their special interest in this client group than having had access to professional formal training.

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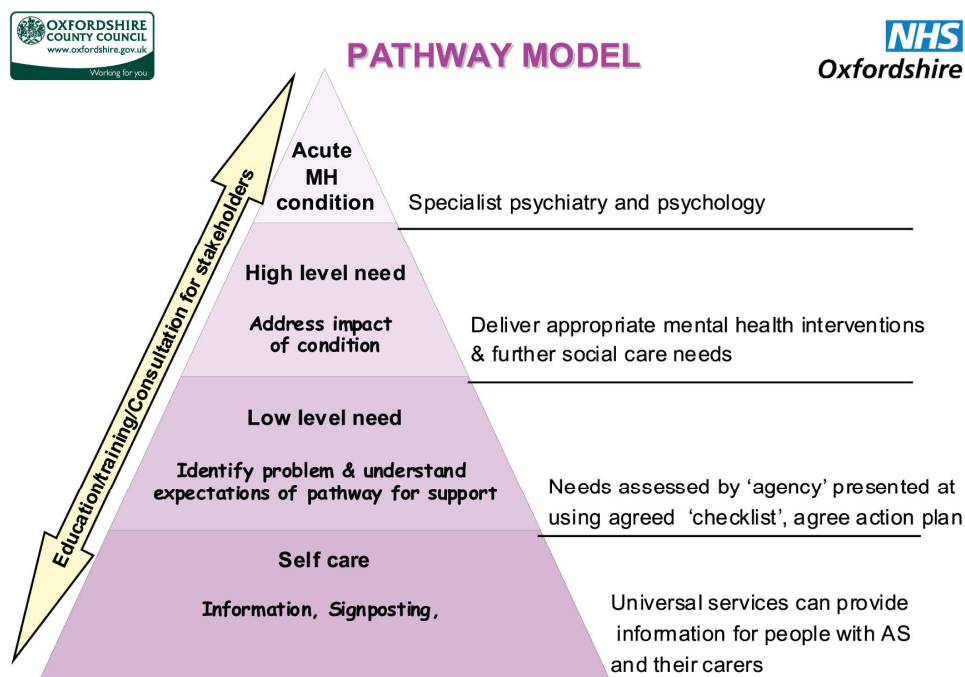
9. There is little AS-specific information and social support for adults and their families in Oxfordshire, other than those provided by the voluntary sector.
10. Those who have had some support from statutory services have often had to reach crisis point before being able to access it and have done so via Learning Disability or Mental Health teams.

### Focus group work

1. People with AS want to be enabled to go to college and to work
2. People with AS want to socialise, make friends and have relationships
3. A key worker/person is needed to ensure services are forthcoming and co-ordinated
4. Good communication between education, health, mental health and social care departments is essential
5. The adolescent years are crucial – at the very time the need for consistent and effective support is greatest, the staff and/or services change or disappear. Transition to adulthood is enough to cope with, transition to different support service staff and set ups is an unnecessary extra burden to young people and their families.
6. The Connexions service is aimed at assisting during the transition period, but many families reported it did not help their young person with AS, and only 2 Connexions advisors with AS understanding were identified across the county by families.
7. A One-stop shop for advice, information, support and advocacy is needed – information is hard to access and services so disjointed that people do not know where to start.
8. Quick diagnosis and immediate post-diagnostic support and needs assessment are essential for teenagers, adults and their families, including siblings and grandparents.
9. Parents and family carers need adequate respite and support services over the long-term to help them in their caring role. Siblings need short breaks and support too – opportunities to be with supportive peers, have fun and not have AS mentioned! They also need help in understanding AS and its pressures on their parents, and why they don't have all the attention they deserve.
10. Supported living accommodation, with careful, well-planned transition from living with parents, is needed by some people with AS and their families now and desired by most at some point.

### 3.2 Stakeholder engagement and consultation

The consultation focussed on the themes and findings from the needs assessment and participants were asked to consider the care pathway model below as a basis for how the needs could be met:



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The consultation was done in three ways. Firstly a workshop which gained good feedback took place on 10 December 2010. Over 100 people – a mix of professionals those with AS and family carers – were invited and 68 attended; these included people with AS and their carers, medical professionals including psychiatrists, representatives from Oxfordshire County Council, NHS Oxfordshire and the probation service and a wide range of voluntary sector organisations with an interest in AS.

Secondly, a survey was also available online and on paper for completion and thirdly, an online discussion group was set up. In all over 500 people were invited to get involved including the Local Involvement Networks; 91 people registered an interest on line and over 100 people took part altogether.

### 3.2.1 Workshop outcomes:

The following topics were picked out as significant by the working groups:

- Individual support - Services need to be personalised and flexible recognising that if diagnosis does not happen early it needs to be available at other points in the journey and that diagnosis should not happen in a vacuum – it must lead to active support of the person with AS through the system.
- Mainstream support
- Training
- Leadership
- Access
- GPs
- Awareness
- Tensions in priorities

In addition five more topics came up in several group discussions – these have been listed in order of prevalence:

- Diagnosis - There seems to be a recognition that what is more important than diagnosis is making sure that services meet needs properly so diagnosis can be informal (i.e. not provided by a medical professional but by someone trained to identify AS) but also followed up with personalised, individual support.
- Links to children's services
- Pathways - There were also several suggestions that models already in place could be utilised to develop services for those with AS. For example piggy backing onto the learning disability friendship and support network system which is already there; using the early issues identification system in schools to extend to identifying those with AS.
- Information
- Finance

### 3.2.2 Online questionnaire and discussion forum topics:

Topics raised in addition to the above included –

- Advice and support
- Transition support from childhood to adult
- Communication between services
- Role of the carer important especially as carers get older – need a plan
- Use existing expertise but at the time and place – across boundaries
- Employment support

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Finally when asked about what strategic approach was needed to take the work forward there was widespread support for an all age autism board with clearly defined objectives and powers to make a difference, it should not be tokenistic.

### **3.3 Summary of consultation findings**

#### **Support**

The importance of appropriate support mechanisms was mentioned as a constant strand through all this work. Support in employment, during stages of transition and support in establishing social networking/relationships were all significantly mentioned as options for development.

#### **Diagnosis**

There was a lot of support for finding new ways to diagnose AS, not only through psychiatric assessment but also through assessment by those who work regularly with this group of patients.

#### **Training**

To support this there would need to be effective training throughout the system. Training in understanding how to work with people with AS was also mentioned in both the workshop and the survey responses.

#### **Pathways**

The use of pathways was also discussed. Signposting should be clear and entry to the pathway should be as easy as possible. But it was also suggested that the pathway needs to be personalised for individuals and carefully crafted to recognise the particular needs of those with AS.

#### **Family carers**

The needs of family carers were important to the respondents of the questionnaire. There needs to be recognition of their expertise and effective support during transition.

#### **Leadership**

This was the topic for the discussion forum and also mentioned in both the responses to the questionnaire and in the workshop. There was wide support for an autism board but no strong views on its reporting and accountability. However it was recognised that the autism board would need to have both clear accountability and more importantly the power to make a difference.

### **4. Local Service Development progress to date**

The project steering group considered all the local and national findings of need and looked at areas where best value for money could be gained. It was agreed to develop the following workstreams with a plan to invest the small amount of resources available to initiate pilot service developments before the end of March 2011.

Four areas were identified and service specifications developed; all designed to help people aged 16 and over with AS. They form part of a pathway that links into and out of clinical pathways, supporting people to self manage in the wider community.

#### **4.1 Pilot service for Oxfordshire AS Alert Card**

Investment:

£10,000

Specification:

The importance of professional training and awareness of how people with AS may present was highlighted as a constant priority, in particular within the Criminal Justice System.

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Many individuals going through the system may not be immediately identified as having AS and therefore their needs may be misunderstood or not met when processed through the Criminal Justice System (CJS), therefore this service specification requires the development and implementation of an Alert Card for people with AS which can be rolled out across Oxfordshire. Work will need to be joined up with Thames Valley Police and other relevant partners to implement a robust process to train staff and enable people to identify themselves as having AS.

The cards should be carried at all times by the individual and can be presented if they find themselves in a situation where they cannot easily explain their behaviour or need additional support.

Improved outcomes against need should include:

- Individual Well being
- Support
- Awareness
- Prevalence data
- Equity of Access

Service Provider:

A proposal to implement a pilot service has been provisionally approved from a local independent organisation and is due to be formally agreed by the steering group at the next meeting on 2 March 2010

### **4.2 Oxfordshire AS Pilot Employment Support Service**

Investment:

£20,000

Specification:

The importance of appropriate support mechanisms was highlighted as a constant priority through all this work, in particular support into employment and ongoing employment support for people with AS, and their employers.

This service specification is designed to help people aged 16 and over with AS take greater control over their lives and promote positive well being which leads to employment. This will be achieved by providing information, support and services in non-clinical settings.

Improved outcomes against need should include:

- Well being
- Employment
  - Increased percentage of people with AS preparing for employment by building their work capacity and skills or looking for work
  - Increased percentage of people with AS entering and/or retaining paid employment
  - Percentage of service Users in Employment
  - Percentage of service users who move on in a planned way
- Equity of access

Service Provider:

Four proposals were submitted to implement a pilot service and one has been provisionally approved from a local voluntary sector organisation and is due to be formally agreed by the steering group at the next meeting on 2 March 2010

### **4.3 Oxfordshire Pilot AS Training Programme**

Investment:

£10,000

Specification:

The importance of professional training and awareness of how people with AS may present was highlighted as a constant priority, notably training in understanding how to work with people with AS was mentioned in both the workshop and the survey responses.

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The needs assessment stated:

'There are some professionals knowledgeable in AS amongst all of the services, but this has more to do with their special interest in this client group than having had access to professional formal training'

The Adult Autism Strategy Statutory Guidance covers general autism awareness training as well as specialised training for staff in key roles. It states specifically that for staff who provide services to adults with autism, autism awareness training should be made available to all staff working in health and social care

This service specification requires a provider to develop a programme of training to different staff groups in NHS and social care with an implementation roll out plan starting in 2010/11 until 2012/13, thereafter training should be able to be embedded in organisations for long term development and to promote behaviour change.

Delivery would include:

- Autism awareness training at a generic level and at more intense level for practitioners likely to come in to contact with people with AS more regularly.
- Training in the first instance to focus on GPs, Integrated Youth Services, Connexions and Housing providers

Improved outcomes against need should include:

- Individual Well being
- Support
- Awareness
- Equity of Access

Service Provider:

A proposal to implement a pilot service has been provisionally approved from a local independent organisation and is due to be formally agreed by the steering group at the next meeting on 2 March 2010

### **4.4 Improving pathway to diagnosis**

A sub group of the steering group has been established to progress this workstream to map current pathways and identify the options available, to include opportunities and barriers to implementation. The workstream should have identified a preferred option by June 2010.

### **5. Local Strategy development**

Since the last scrutiny report, the publication of the statutory guidance and the feedback from the consultation further discussion with children's services partner has taken place and we have begun to move forward work on a strategic approach which spans the whole autism spectrum across adults and children. This has not deflected from our original remit to continue with the strand of work around AS as is illustrated above in the current workstreams identified.

This broader strategy development will need a longer timescale to develop and will be driven by the Autism Partnership Board which is planned to be established by September 2011.

Further discussions will also be needed to establish a robust governance structure for the Autism Partnership Board.

### **6. Next Steps**

During 2011/12 the following work will be progressed:

- Complete formation of an all age Autism Partnership Board with leadership, agreed membership, Terms of reference and governance across LA and NHS.



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- Complete pilot service development projects with evaluation reports and recommendations for further roll out.
- Identify, and invest in, a clear care pathway to diagnosis or formal assessment of needs
- Consider a cost benefit analysis of funding a ASD coordinator/liaison role to act as a central resource for individuals and organisations engaged in the care pathway.

JL/22/2/2011

## Appendix A

### Glossary:

#### AS

Aspergers syndrome and other autistic spectrum conditions with no co-existing learning disability

#### Autism

The National Autistic Society (NAS) defines autism as: a lifelong developmental disability. It is part of the autism spectrum and is sometimes referred to as an autism spectrum disorder, or an ASD. The word 'spectrum' is used because, while all people with autism share three main areas of difficulty, their condition will affect them in very different ways. Some are able to live relatively 'everyday' lives; others will require a lifetime of specialist support.

The three main areas of difficulty which all people with autism share are sometimes known as the 'triad of impairments'. They are:

- difficulty with social communication
- difficulty with social interaction
- difficulty with social imagination.