Summary of the Asperger’s syndrome needs assessment
October 2010

1. Introduction
These are the important things from the needs assessment for people aged 14 and above with Asperger’s syndrome in Oxfordshire

2. Background
In England about half of all people who have autism also have a learning disability. A learning disability means you have an IQ below 70.
People with autism and a learning disability may receive support and services from learning disability teams.
People with autism who have an average, or above average IQ, (people with Asperger’s syndrome or high functioning autism), often find it difficult to get support or understanding of their needs.

This report is about people who have average or above average IQ (people with Asperger’s syndrome or high functioning autism).
The Autism Act, 2009 and the National Autism Strategy, 2010 say there is a lack of services for people with Asperger’s syndrome or high functioning autism.

People with Asperger’s syndrome or high functioning autism have not had a clear route to assessment, diagnosis or support.
Neither mental health teams, nor learning disability teams have supported people into services.
In Oxfordshire there has been a growing interest in the needs of this group of people. Parents of people with Asperger’s syndrome or high functioning autism have campaigned for action from public services.

The Better Mental Health in Oxfordshire consultation said more services for people with Asperger’s syndrome or high functioning autism were needed.

3. How many people with Asperger’s syndrome or high functioning autism?
It is difficult to count the number of adults with autism.
It is more difficult to count the number of people with Asperger’s syndrome or high functioning autism.
There is a lack of information on how many people with Asperger’s syndrome or high functioning autism there are because of difficulties caused by:

− no diagnosis
− inaccurate record-keeping Asperger’s syndrome data has not been needed in the past
− some double counting

The gap between estimated national numbers of people and current service provision is wide.
There is only a limited amount of money and time currently available for this project to improve the care pathway for people with Asperger’s syndrome or high functioning autism. The project will not meet all people’s needs. The project will need to make important decisions about doing the best thing.

Recent estimates:
- 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
- around 2,500 people in Oxfordshire are likely to have Asperger’s syndrome or high functioning autism

4. National guidance
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

The national strategy ‘Fulfilling and rewarding lives’, the ‘strategy for adults with autism in England, was published in March 2010. This national strategy will be reviewed in 2013. It looks at:
- 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 Asperger’s 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
- enabling local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities

Statutory guidance for local authorities and the NHS on the national Autism Strategy is due to be published by 31st December.
This statutory guidance must include:
1. Provision of relevant diagnostic services
2. Identification of adults with autism spectrum conditions
3. Asperger’s assessment of needs for relevant services
4. Planning of relevant services for people moving from children’s to adult services
5. Planning of relevant adult services
6. Staff training for those who provide such services
7. Local arrangements for leadership on relevant services
8. Best practice examples of effective local services for adults with autism
9. Examples of personalisation working successfully to give adults with autism more control over the social care they receive
10. Details of what information adults with autism and their family or carers are likely to need after diagnosis.
The National Autistic Society, the National Audit Office and other organisations say there are 5 themes:
1. Diagnosis and support
2. Help in the community
3. Employment and other Meaningful activity
4. Housing and support
5. Health

These 5 themes form the framework of the Needs Analysis research undertaken in Oxfordshire.

5. Oxfordshire Asperger’s syndrome Project Progress to date
The steering group has looked at the key needs and the responsibilities set out for local authorities from the National Autism Strategy. Oxfordshire’s progress is set out below.
This includes further work based on the findings of the needs Asperger’s assessment:

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<tr>
<th>Responsibilities</th>
<th>Oxfordshire</th>
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<tbody>
<tr>
<td>A Joint commissioner/ senior manager should have clear commissioning responsibility for adults with autism</td>
<td>Fenella Trevillion leads for Asperger’s syndrome and high functioning autism Ann Nursey leads for Autism and Learning disability</td>
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<tr>
<td>A commissioning plan around services for adults with autism should be developed which reflects the Joint Strategic Needs Analysis and all other relevant data on prevalence</td>
<td>Data gathering is well under way, draft report is being prepared, on which strategy and commissioning plan will be based.</td>
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<tr>
<td>A local Autism partnership board should ideally be developed – see Appendix 3 for possible structures reflecting best practice</td>
<td>Asperger’s syndrome project steering group established and operating effectively. Discussion to be had Asperger’s syndrome to whether this transforms into partnership board</td>
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<td>A lead professional should be appointed to develop diagnostic and Asperger’s assessment services for adults with autism</td>
<td>To be decided</td>
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<tr>
<td>The views of adults with autism and their carers must be sought and taken into account in the development and delivery of local services</td>
<td>Focus groups have been held, with information collected also from telephone calls, emails and letters; consultations on draft strategy to follow</td>
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<tr>
<td>Information about the numbers of adults with autism should be recorded and shared</td>
<td>Awaiting national protocol. Improved recording starting with introduction of diagnosis recording on the health and social care client record systems</td>
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<tr>
<td>There must be a clear care pathway to diagnosis by 2013</td>
<td>Awaiting NICE guidelines and local commissioning plan;</td>
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Ridgeway Partnership currently provide some autism spectrum conditions diagnoses locally

From June 2010, strategic planning mechanisms/processes must be in place – with meaningful representation from adults with autism and their carers

Asperger’s syndrome project steering group established; Kathy Erangey, qualified expert by experience and family carer, representing carers and working with Primary Care Trust and Oxfordshire County Council on needs analysis and draft report; 3 young people with Asperger’s syndrome have begun to attend meetings to give their views; People with Asperger’s syndrome having taken part in Focus Groups could form nucleus of an email reference group; Family members having taken part in focus groups could form nucleus of reference group or email reference group

6. The position in Oxfordshire

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

The key findings from this are:

Survey of services
1. A lack of Asperger’s syndrome-specific adult services in Oxfordshire
2. Not all places in Oxfordshire have services
3. A need for training and awareness amongst main-stream school staff
4. Oxfordshire has a highly skilled hub of Asperger’s syndrome expertise within the education service for autism.
5. This expertise is spreading to some further education colleges.
6. Some young people with Asperger’s syndrome are able to access some social support (directly or indirectly) from Oxfordshire County Council children with disabilities services.
7. Once young people with Asperger’s syndrome leave education or become 18 years old, there is very little support for them
8. There are some professionals knowledgeable in Asperger’s syndrome 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.
9. There is little Asperger’s syndrome-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 Asperger’s syndrome want to be enabled to go to college and to work
2. People with Asperger’s syndrome want to socialise, make friends and have relationships
3. A key worker/person is needed to ensure the person gets services and these are co-ordinated
4. Good communication between education, health, mental health and social care departments is essential
5. 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. Connexions service is aimed at people with Asperger’s syndrome during the transition period, but many families reported it did not help their young person with Asperger’s syndrome. Only 2 Connexions advisors with understanding about Asperger’s syndrome were identified across Oxfordshire 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 Asperger’s syndrome mentioned! They also need help in understanding Asperger’s syndrome 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 Asperger’s syndrome and their families now and desired by most at some point.

### 7. Next Steps

**Planning**
Workshop planned for 10th December for all involved stakeholders and service users and carers.

*Outcomes to include:*
- Agree needs and pathway broadly correct
- Prioritise what needs to be done/delivered; how could current providers contribute to pathway.

**Process**
1. Produce action plan, stepped care service model and draft service specification(s) informed by the workshop.
2. Scope options around provision to include options for:
   - Current contract variations within 2010/11
   - Procurement re-tender or any willing provider