



Aspergers Syndrome

**~ A Needs Assessment of people
aged 14 and over in Oxfordshire ~**

By

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Version 5 - 20 October 2010

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1. Acknowledgements

The authors would like to thank everyone who helped in the gathering and collation of the information in this report. Particular acknowledgement is due to the people with Aspergers Syndrome (AS) and parents and carers who have been very open and willing to share their often very painful, stressful experiences. This report is far richer for your moving stories and the information you gave us - thank you very much.

In addition thank you service provider staff from statutory and voluntary sectors across Oxfordshire, we acknowledge that it was a time-consuming and probably tedious process to collect the data requested and we thank you for your hard work and co-operation.

And to the volunteers who helped at the Focus Groups, and particularly those who collated the data afterwards – thank you very much.

Lastly, thank you to a lot of very busy people from other areas willingly shared information, experiences and lessons learned from developing and working within AS services - we thank them for their generosity and time.

Finally, Fenella Trevillion and Ann Nursey would like to send special thanks in particular to Kathy Erangey and Martin Mellors, Juliet Long, and all members of the Oxfordshire Aspergers Project Steering group, for their enthusiasm, commitment and desire to make things happen in partnership, even when faced with such limited resources. It has been a momentous achievement to successfully bring all this information together into this document in a relatively short time to provide a robust platform from which decisions can be made about future commissioning requirements.

2. Introduction

2.1 Setting the scene

This report presents the work progressed to date in scoping the key needs of people aged 14 and above with Aspergers Syndrome (AS) in Oxfordshire and will be used to inform the next steps required to commission a care pathway to meet those needs within the limited resources available.

It is estimated around 50% of people who have autism also have a learning disability (IQ below 70) and may 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 themselves and their needs. It is this group of people to whom the work described in this report relates. The needs of people who have autism and a Learning Disability are addressed in Oxfordshire's Learning Disability Commissioning Strategy. This reflects the principle of the Government White Papers 'Valuing People' and 'Valuing People Now!'

Historically, people with AS 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 and parents of people with AS have campaigned for action from the statutory sector.

As part of the consultation for the Better Mental Health in Oxfordshire (BMHO) commissioning strategy 2009-12, feedback was received that more services were needed for people with AS.

The lack of services for people with AS is acknowledged in the Autism Act which was passed in late 2009, and the National Strategy for people with Autism published in March 2010.

This document fulfils the undertaking given nationally in the Autism Act and locally in the BMHO strategy to establish the needs of this group and make recommendations for future commissioning actions.

2.2 AS Project Steering Group

A steering group was formed to oversee a needs analysis of people with AS in Oxfordshire and the compilation of this report. The Steering Group members are listed below:

Organisation	Name	Job Title
NHS Oxfordshire	Fenella Trevillion	Head of Integrated Commissioning (Lead on Mental Health)
	Martin Mellors	Service Development Manager (MH)
	Dr John Galuszka	Medical Director
Oxfordshire County Council	Paul Purnell	Head of Adult Social Care
	Ann Nursey	Asst Head of Service, Adult Social Care & Joint Commissioner (Lead on adults with Learning Disabilities)
	Simon Kearey	Head of Strategy & Transformation

	Janet Johnson	Strategic Lead SEN/LDD/Transition
OBMH (Oxon & Bucks Mental Health)	David Bradley	Chief Executive
	Sam Gillanders	Clinical Project Manager
Ridgeway NHS Partnership	Dr Sally Powis	Senior Clinical Psychologist
National Autistic Society (NAS)	Rachel Pike	South West Regional Co-ordinator
Autism Family Support	Gita Lobo	Project Manager
Autism Oxford	Catherine Black	Self-advocate & Autism Speaker
	Paul Isaacs	Self-advocate & Autism Speaker
	Lindsay Smith	Self-advocate & Autism Speaker
	Kathy Erangey	Family Carer & AS Project Consultant

2.3 Current economic climate and resources

The response to this needs assessment is being planned in a time of unprecedented reductions in funding for public services. Radical changes to the structure of the NHS are also underway, with uncertainty about the nature of future commissioning arrangements. In this context it is important to be realistic about the limitation on new resources available for developments.

A sum of £95,000 has been identified from mental health budgets for the financial year 2011-12, and this will recur in future years. This means that some of the service responses that would be desirable cannot be delivered at this time. Depending on the outcome of discussions around service models, a decision will be taken as to whether a tender will be necessary for any service developments.

However, many of the changes that will make a difference to the lives of people with AS do not require new investment. They are about people doing things differently, having an improved awareness and understanding, and working together. As the needs analysis shows, there is already a lot of money being spent to support people with AS through mental health or learning disability services, and some through the voluntary sector, and this will continue where appropriate. Over time, it may be possible to develop better and more cost-effective ways of supporting some of the existing people, and to prevent others from requiring intensive services, and this may free up money which can be invested in AS-specific services.



3. Terminology

This report focuses on people with Aspergers Syndrome and it is important to first understand the different terminology associated with Autism and Aspergers.

'Autism', 'The Autistic Spectrum', 'Autistic Spectrum Disorder' (ASD) and 'Autistic Spectrum Condition' (ASC) are amongst the terms commonly used to describe a vast range of difficulty, need and ability. Aspergers syndrome (AS), or high-functioning autism (HFA) is often used to describe the more able end of the autism spectrum. There is much debate amongst professionals in the field as to whether there is a difference between the two, but this is outside the scope of this piece of work. For the sake of brevity, 'AS' will be used throughout this report to mean 'Asperger's syndrome' and/or 'high-functioning autism'

3.1. Autism

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 unexpected 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.

3.2 Aspergers Syndrome

Aspergers syndrome is a form of autism. People with Aspergers 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 of average or above average intelligence.

AS has been described as; "*an absence of the instinctive aspects of social life*" (Professor Digby Tatum)

It is crucial to understand that AS is not a mental illness, but is a life-long disability, albeit one which cannot be seen. Research has shown that the brains of people with AS are different in structure and also in the way they process social information, particularly with regard to human faces and social situations (Baron-Cohen, et al., 1999). People with AS often use just the words they hear to understand the thoughts and intentions of others and this puts them at a great disadvantage in a social world where people rarely say what they really think and/or mean. They are also likely to have a reduced awareness of emotion (within themselves and others), and to find it more difficult to regulate their emotions.

Many adults with AS have published their writing in recent years, some using poignant prose and poetry which express their feelings of bewilderment, confusion, isolation and yearning to feel they 'belong' (Hale, 1998; Lawson, 2001). One moving example includes the lines:

"I live in a world so alien to me, How did I get here? Why am I so different? Wanting to be like the rest of you, but not knowing how to fit into your world" (Stonehouse, cited in Henault, 2002)

Please see **Appendix 1** for a comprehensive outline of AS characteristics and **Appendices 13** and **14** for questionnaires to aid diagnostic assessment, developed by Professor Simon Baron-Cohen of Cambridge University.



4. Background

4.1 Historical context

Autism was first identified by Kanner in the 1940s. The condition he described, sometimes referred to as 'Kanner's autism', was what we now recognise as being at the more severe end of the autism spectrum. Kanner's work was published and has been widely recognised since the 1940s. At roughly the same time in the 1940s, and without knowledge of Kanner's work, Hans Asperger identified a group of 'autistic' patients who were of high intelligence but had significant difficulties in everyday life.

Hans Asperger's work remained unrecognised for the next 40 years until, in 1980, Dr Lorna Wing translated his paper into English. This was a key element in why health and social care services, and training for medical and social care staff, developed without recognition of the unique difficulties faced by people with AS.

4.2 National Context

4.2.1 Strategic recognition for people with Aspergers Syndrome

Traditionally, health and social care services in England have been set up to provide either for people with Learning Disabilities (currently defined as those with an IQ of less than 70), or for people with Mental Health problems. People with AS have an IQ of average or above and, unless they also have a mental illness, they do not fit into either service.

In addition, when 'Valuing People' was published by the government in 2001, it specifically excluded people with AS. This error was corrected in the Health Service Circular on Implementation in August 2001, but was never widely recognised by service providers and consequently, people with AS have been consistently assessed as not meeting the criteria for either Learning Disability or Mental Health services.

In response to the growing demand for action from the National Autistic Society and public pressure on MPs, the Department of Health (DH) published in 2009 'Better Services for People with Autistic Spectrum Disorder'. A letter was circulated to Directors of Social Services raising the profile of this group, and a flurry of related publications followed. Also in 2009, the DH published "Services for adults with autistic spectrum conditions (ASC) – good practice advice for primary care trust and local authority commissioners", and in May of the same year, a consultation on the future strategy for Adults with Autistic Spectrum Condition – 'A Better Future' - was published by the DH requesting a response by 15th September 2009. These responses were collated and fed into the Autism Act.

The 'Autism Act' was passed in late 2009, and sets out a timetable for the publication of statutory guidance for Local Authorities regarding the planning and provision of services for adults on the autistic spectrum.

'New Horizons, A shared vision for mental health' was published in December 2009. It sets out a cross-government programme to improve both the mental health and well-being of the population and the quality and accessibility of services for people with poor mental health. A key part of this is prevention and helping both the general population and high risks groups with their mental health. Evidence indicates that those with AS are very much within the high risk category if no support services are available. The New Horizons programme has a clear focus on prevention and focuses on similar issues to

those in this report, such as recognising and utilising the role of families and carers, making services more inclusive and improving transition from childhood to adulthood. It also references the National Autism Strategy as dealing with more specific issues for adults with autism.

People with AS have a higher incidence of mental health problems than the general population. “33% of adults with autism have experienced severe mental health difficulties because of a lack of support” (NAS, 2008). Traditionally, referrals have been made to mental health service teams, 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.

In March 2010, ‘Fulfilling and rewarding lives’, the ‘strategy for adults with autism in England’ was published as required by the Autism Act, 2009. The strategy has a planned lifecycle of 3 years, before it is formally reviewed in 2013. Statutory Guidance for Local Authorities and the NHS on the implementation of the national Autism Strategy is due to be published by 31st December, 2010.

See **Appendix 2** for a list of publications relating to adults with autism and their support needs.

4.2.2 Financial impact if there was specialist service provision

It is recognised within Oxfordshire there are very limited existing resources available to meet the needs of people with AS but it is hoped the investment available would help to develop some early intervention specific services and save costs elsewhere in the long term.

The 2009 National Audit Office (NAO) report, *Supporting adults with autism through adulthood*, stated that there is a greater than 99% chance that providing a specialist service for 8% of adults identified with AS will save £67 million to the public purse and if 14% of adults were identified, the savings could be £159 million.

However, it is very important to understand that these savings would be realised throughout the entire public sector system and not just within health and social care, so they would include savings from employment benefits, within the criminal justice system and elsewhere.

Costs of prevention services are often difficult to fully itemise, particularly for groups such as those with AS, who are currently under-served, and there remains the risk that providing services will, to some degree, create further demand for them, along with related costs.

4.3 Local Context

4.3.1 Current situation for people with Aspergers Syndrome

About half of people who have autism also have a learning disability and in Oxfordshire 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 County Council.

People with AS have an IQ in the normal range or above and so do not meet the criteria for learning disability services. Historically, people with AS 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 AS have campaigned for action from the statutory sector. Locally there are no dedicated services for people with AS although a number of people with the diagnosis of AS are the users of mental health or learning disability services, or access the few services for those with autism more generally, such as the Autism Family Support service, Kingwood Trust or generic supported employment services.

4.3.2 Local strategic direction

2008 NAO Survey - In September 2009 the National Audit Office sent out a survey to all Directors of Adult Social Services. The information sent from local authorities was compiled by the NAO and returned to each authority. Oxfordshire's response is not included here as it was apparent that reliable figures were not available for this submission. The estimates given within this report are considered to be more accurate.

Better Mental Health in Oxfordshire (BMHO) 2009-12 is the commissioning strategy for mental health services in Oxfordshire. As part of the consultation for the BMHO strategy, it was highlighted that more services were needed for people with AS. This AS strategy document is a direct descendent of the BMHO strategy, and fulfils the undertaking given in the BMHO strategy to establish the needs of this group and make recommendations for future commissioning actions.

From Supported to Independent Living (SIL), Oxfordshire mental health and housing and support strategy 2009-13, recognises the high costs incurred to provide accommodation and support to small numbers of people with AS. As a result of this, people with AS are included as being eligible for the services commissioned as part of the SIL strategy. However, additional, AS-specific support is likely to be needed to enable SIL services to fully support people with AS.

In 2009 an Oxfordshire AS Steering Group was established with multi agency and service user and carer membership. The national and local strategic direction has informed the work of the group and the actions taken to date include undertaking this needs analysis which is described in detail in section 6 and the future way forward set out in section 7.

5. Literature Review

In recent years a number of documents have been published relating to adults with autism and their needs and how best to support them (see **Appendix 2** for a list showing some of these). The NAS has published the findings of several research projects and the Government has issued guidelines with examples of good practice.

5.1. Research Projects and Guidelines

Taking Responsibility (2002), published by the NAS, set out good practice guidelines for services for adults with Asperger Syndrome. The report highlighted that across the UK, adults with AS were explicitly excluded from accessing statutory health and care because they did not fit the criteria for LD or MH services. It also said:

- 65% of adults with AS had not received a Community Care Assessment
- Adults with AS were often denied appropriate support at college and university
- Adults with AS were often excluded from housing and employment opportunities due to lack of understanding and resources. ¹

Between 1995 and 2002, 17 pieces of research consistently reported the same list of needs amongst adults with AS.

The following study was conducted by Keith McKenzie, an adult with AS:

The Asperger's Syndrome Survey (McKenzie, 2004)

McKenzie (2004, unpublished), asked 62 people with AS, about the topics they would most like to have included in a conference for people with AS.

The topics requested included:

- Socialising – 81%
- Relationships – 75%,
- Friendships – 71%

Participants were also asked what subjects they find difficult to manage.

The replies included:

- Dealing with others – 69%
- On the spot decision making – 68%
- Being understood – 66%
- Socialising – 60%

The NAS research report **I Exist** (2008)² found that adults with autism are often isolated, unable to access support and are dependent on their families. The report states that:

- 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

¹<http://www.autism.org.uk/about-autism/autism-library/magazines-articles-and-reports/reports/other-reports/taking-responsibility-good-practice-guidelines-for-services.aspx>

²<http://www.autism.org.uk/nas/jsp/polopoly.jsp?d=1558&a=15394>

- 60% of parents say that a lack of support has resulted in their son or daughter having higher support needs in the longer term
- 61% rely on their parents financially
- 40% live with their parents
- 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)
- 67% of Local Authorities do not know how many adults with autism are in their area
- 65% of Local Authorities do not know how many adults with autism they support

Good Practice in supporting adults with autism: guidance for commissioners and statutory service³ was published by DH in 2009³. It said that it is crucial that all local areas should develop an autism planning group, and provided guidance on how to improve the lives of adults with autism, citing examples of good practice across the country:

- Multi-agency planning – Gloucestershire and Leicestershire & Rutland
- Mapping and Commissioning – Cumbria, Wokingham & Lewisham
- Diagnosis and Assessment – Liverpool & Somerset
- Training and Awareness – Training Providers, Cornwall, Surrey & Oldham
- Transition – Northamptonshire, City College, Norwich & Bath & NE Somerset
- Employment – Surrey, Goldman Sachs & Autism West Midlands
- Supported Living – Kingwood Trust, Surrey & REACH
- Preventative Services, Social Inclusion – Oldham & RB of Windsor & Maidenhead
- Specialist Autism Teams and Centres of Excellence – Nottingham & Manchester
- Personalisation and self-directed support – Doncaster, Bury & Coventry

In June, 2009, the National Audit Office published its report ***Supporting Adults with Autism throughout Adulthood***⁴.

Its main findings were that improvements were needed to make services more effective:

- Better strategy and planning, based on good information
- Raising levels of knowledge and awareness of the nature of autism and the potential needs of autistic people
- Better targeted support for people with AS

During its research, the NAO surveyed GPs and found:

- 80% of GPs require more training in autism to identify and better manage patients
- Adults with undiagnosed AS are generally referred to Adult Mental Health Services (54%)
- Older people with undiagnosed AS are mainly referred to Older People's Mental Health services (73%)

³

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_097418

⁴<http://www.nao.org.uk/publications/0809/autism.aspx>

5.2 Statutory Guidance

The Autism Act 2009⁵ - The Autism Act specifically requires development of a strategy 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, NHS bodies and NHS foundations trusts.

Statutory guidance to secure the implementation of the autism strategy must be published by 31st December 2010. This statutory guidance must include:

1. Provision of relevant diagnostic services
2. Identification of adults with Autism Spectrum Conditions
3. Assessment of needs for relevant services
4. Planning of relevant services for those in transition 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

Fulfilling and Rewarding Lives - The Strategy for Adults with Autism in England (2010)⁶ This strategy sets a direction for long-term change and identifies specific areas for action over the next three years and is underpinned by the fundamental principles of equality and human rights. It is based on a wide range of existing government policy – from health to social care to employment to justice to communities – that should already support adults with autism. The government says the strategy does not depend on new investment, but relies on the approach of ensuring mainstream services actively identify and respond to the needs of adults with autism.

The Government's Vision is:

“All adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents”

This is identified as meaning:

- having a right to receive an assessment of need from social services
- getting the same opportunities for education and further education as everyone else
- being supported to get a job and stay in work
- being able to choose where to live – just like anyone else
- having relationships and social networks

⁵ http://www.opsi.gov.uk/acts/acts2009/ukpga_20090015_en_1

⁶

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_113405.pdf

- having their health needs properly met in a way which is appropriate for someone with autism
- being safe from hate crime and discrimination
- living in a society where people understand, respect and accommodate difference, and
- receiving support to live independently, as appropriate

It is recognised in this literature that adults with autism and the people who care for them have often been badly let down by public services which have failed to recognise or respond to their needs – and that this must change:

“Achieving [the vision set out above] requires a cultural shift, where the complexities and challenges of autism are understood not only by public services but also more widely within society”

The National Autism Strategy will be formally reviewed in 2013 and during the next three years, it 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

5.3 First year delivery plan 2010/11

The first year delivery plan was published on 2nd April 2010, with priority actions, including the development of regional delivery plans. Some of this plan is laid out below – for a fuller summary, please see **Appendix 3**.

The primary focus of the first year is on the setting up of the governance arrangements and structures needed to drive future change, and the development of the statutory guidance and longer-term delivery plan, both to be published, with milestones, timings and measures of success, by December 2010. A public consultation process is in progress, which will end on 22nd October 2010. The responses are expected to inform the statutory guidance.

Three key tiers of governance are being formed to oversee national delivery and monitor progress of the Autism Strategy:

1. The Adult Autism Strategy Programme Board will provide overall governance, and is accountable to, and chaired jointly by, The Minister for Care Services and the Director General of Adult Social Care
2. The Delivery Group, will report to the Programme Board, with a National Implementation Manager reporting to the Delivery Group
3. DH Deputy Regional Directors of Social Care and Partnerships will oversee progress on a regional level, working closely with local leads. They will produce a regional action plan by 31st March 2011, showing key milestones and deliverables, based on the findings of an analysis/scoping exercise

The Director of Adult Social Services (DASS) should ensure that in each local area there is “a *joint commissioner/senior manager who has a clear commissioning responsibility for adults with autism*”

The first year plan says it is essential that:

- Adults with autism and their families and carers, representative organisations and professionals in the field are involved during the implementation of the autism strategy
- Clear processes for regular communication and consultation with adults with autism and their representatives must be put in place

National examples of best practice in stakeholder involvement will be identified and published by March 2011.

A summary of other selected sections of the first year delivery plan are outlined below:

Pathway for diagnosis

- NICE is developing a clinical guideline, to include diagnostic processes and a model care pathway, which will form the foundation for local commissioners to develop referral and care pathways in their areas. The publication date for this guidance is not yet known. (NICE guidance on recognition, referral and diagnosis of autism in children and young people is due for publication in September 2011, the remit having been received from Government by NICE in August 2007).
- The lead professional in each area will examine existing services and act on the model pathway set out by NICE
- There is to be a clear pathway to diagnosis in every area by 2013

From diagnosis to assessments

- A diagnosis of autism will trigger the duty to assess under the NHS and Community Care Act 1990 - the strategy makes this explicit
- A diagnosis of autism will also trigger a carer’s assessment
- Adults with suspected autism do not need to wait for diagnosis to request a community care assessment.

Giving adults with autism more say in their care and support

- Suitable services and support will be developed in time to enable the right to choice and personalised services to be realised

Help into work

Employment support proposals to be published shortly, with timetable for delivery

Supporting Local Government to adapt

- Local areas to set their own priorities and guide resources
- Revenue streams to be reduced, less ring-fencing for LAs
- Guidance to be published on aligning and pooling local budgets to frontline services – eg joint ventures by LAs and partners
- Reports, Inspections and Assessments to be reduced and co-ordinated

Regional planning and local planning

- Regional delivery plans for adults with autism to be developed

- From June 2010, strategic planning mechanisms/processes to be in place – with meaningful representation from adults with autism and their carers
- Local areas to develop their own commissioning plans, having gathered the necessary data
- DH will develop an organisation self-assessment tool for local areas to evaluate/measure progress – by end December 2010
- DH will provide sample business cases for local partners to use to support the setting up of local specialist autism teams – by end December 2010
- DH is leading development of a protocol for recording and sharing information about adults with autism – to be complete by end December 2010
- Health and Social Care bodies to ensure they meet their equalities duties, especially those under Disability Discrimination Act

Developing local governance structures

The value of establishing a Local Autism Partnership Board, bringing together different organisations, services and stakeholders and setting a clear direction for improved services is highlighted. See **Appendix 4** for details of four different examples of structures which have worked in Cornwall, Gloucestershire, Greater Manchester and the North East.

5.4 AS and Autism in our Criminal Justice System

There is no screening for autistic spectrum conditions (ASCs) in prisons, nor within probation services, but it is suspected that unless clearly diagnosed beforehand, most will be missed. It is believed that people with an ASC are seven times more likely to have contact with the Criminal Justice System than the average person (Curry, et al, 1993). According to the Berkshire Autistic Society, which recently launched an Autism Alert Card in conjunction with Thames Valley Police, 35% of Anti Social Behaviour Orders (ASBO) are issued to young people with mental health problems – and it is thought that 90% of these have an ASC.

A recent publication from the NAS and the Association of Chief Police Officers suggested that it was higher functioning people with ASCs that were likely to come into contact with the criminal justice system – probably because of the challenges and lack of opportunities and understanding they face. There was some evidence that knowledge amongst clinical prison staff about AS poor. Also the report indicates there may be a high volume of people with marked and borderline learning disability in our prisons.

Some research has been done in the Scottish Prison Service, where 49 prisoners were identified from 1,000 screenings (approx 5%) as potentially on the autism spectrum. If the incidence is at least that of the general population, there would be around 850 with ASC in prisons across England and Wales, but if the Scottish research is used, this figure could be 5 times higher - at 4,250. The NAS says that there is currently research in progress to investigate this.

6. Oxfordshire Needs Analysis

6.1. Methodology

We have used several routes to gaining information and data for this needs analysis report. These are summarised below. These different routes have been used to give an overall good coverage of information and attempt a level of robustness through cross-referencing and correlating the information. This has been needed as information on AS is often held in several different places, in different ways - and often there is little or no information at all. The National Audit Office's report "Supporting Adults with Autism throughout Adulthood" states that many local authorities found it difficult to gather and provide information, and Oxfordshire acknowledges it was one of them.

The Oxfordshire AS Project Steering group believe the information presented gives a good indication of the broad level and type of need, but is unlikely to be totally complete or inclusive.

6.2 Prevalence

The following excerpt from the website of the NAS summarises 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."

In terms of numbers, 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; National Autistic Society [NAS] website, 2010). In Oxfordshire, this would suggest there are in the region of 5,000 autistic adults.

The report 'Oxfordshire Care Pathway Project: Children and Young People with Autistic Spectrum Disorder' (2009), commissioned by Oxfordshire PCT Children's Services, suggested there may be 1,500 children under 18 years and 4,556 adults with autism in the county. Around 50% of autistic people are likely to have AS or high functioning autism. Using these figures, there may be a minimum of 2,278 adults with AS in Oxfordshire. Estimates from Autism Family Support (Children in Touch) in Oxfordshire suggest there could be as many as 3,900 people aged 14 years and above with AS in the county.

6.3. Current service provision

Questionnaires were sent to a range of statutory and voluntary sector providers who support people based in Oxfordshire, requesting information about services provided, costs, numbers of people etc. Some with large caseloads were approached directly for further information and contribution. One of the key issues with AS is, of course, diagnosis, and this itself makes data collection more difficult – if someone has symptoms

similar to AS, but no diagnosis, uncertainty arises regarding their inclusion in this study. We have taken the view to be as inclusive as possible, and tried to convey this to providers. However, this issue would seem to indicate the potential for under-reporting in this area or over-reporting. There was evidence of people who clearly met LD criteria being included in some lists from providers.

Increasingly, support for people with AS 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.

In order to cover all of these areas, service provision was analysed using the five themes identified by previous research by the NAS, NAO and other organisations:

- Diagnosis and Support
- Help in the Community
- Employment and Other Meaningful Activity
- Housing and Support
- Health

6.3.1 Diagnosis and support

There is currently no dedicated service for assessment and diagnosis of AS in Oxfordshire. Until December 2009, a few people were able to receive an appropriate Tier 4 Mental Health Service referral to receive this service from Professor Anthony Bailey at the Warnford Hospital, but he has now left his post and this has not been filled. There are other skilled, experienced clinicians in Oxfordshire - specifically within the Ridgeway NHS trust and one CAMHS team - with a particular interest in AS, but their remits are to work only with people with a learning disability or with mental health needs.

Despite the fact that 54% of GP referrals of adults (and 73% of the elderly) with undiagnosed AS are to MH services, there is only one part-time Child and Adolescent Neuro-Psychiatrist for the whole of Oxfordshire and we have not been able to identify any adult MH clinicians with a specific, formal AS expertise. Therefore, general CAMHS and OBMH doctors receive most of the referrals. The fact that there are no designated AS adult services means that most doctors do not have the experience to recognise the needs of parents and/or teenagers and adults with AS – and this is not covered in their adult mental health training. It is quite common that parents become aware that they themselves have AS only after their children have been diagnosed. In addition to this AS in females is even less understood, so there is a further need to have designated services to address the needs of girls and women.

There is virtually no AS-specific diagnosis or post-diagnostic support for adults in Oxfordshire – what exists is ad hoc and often the result of personal interest and dedication by particular individuals working outside the parameters of the services they normally provide.

6.3.2 Help in the Community

6.3.2.1 Autism Family Support (Children in Touch)

‘Autism Family Support’ (AFS) is a project of ‘Children in Touch’, the Oxfordshire charity supporting autistic children. AFS offers information and support to families of children

and young people on the autism spectrum in Oxfordshire, and its core funding is from grant-making bodies.

The project manager at AFS is very highly regarded by people with AS, their families and professionals alike, but AFS is also hugely oversubscribed and without long-term core funding. The project offers information and support services to families of children and young people on the autism spectrum in Oxfordshire.

Services offered include a befriending scheme, several youth groups, school holiday activities for AS teenagers and support for the Oxford Aspies adult social group. The project also works with professionals in developing support services and offers bespoke training.

More information about the service can be found in **Appendix 10**.

6.3.2.2 Autism Oxford

Autism Oxford offers affordable autism speaker events to raise awareness of the particular strengths and difficulties of people on the autism spectrum and strategies which have helped. The speakers are either highly regarded professionals in the field, people with autism, or both. Ten young adults with AS attend monthly speaker group meetings for coaching in public speaking and social interaction. They are then paid to speak at events to large audiences of family members, people with AS and professionals from a wide variety of backgrounds.

6.3.3 Employment and other meaningful activity

There is very little support for people with AS to seek and find employment and then keep it.

6.3.3.1 OCC CYP&F (Children, Young People & Families) Education Service for Autism.

This service forms part of **CISS** (Communication and Interaction Support Service), which comes under **SENS** (Special Educational Needs Support Service). There are 800 children and young people (aged 5–19 years) with autistic spectrum conditions being supported by the Service for Autism. The majority are in mainstream schools, with others in special schools and 64 in the **Autism Resource Bases** (now Communication and Interaction Bases) which are attached to mainstream (4 primary and 4 secondary) schools.

An outreach team of **Autism Specialist Advisory Teachers** visits schools and supports the teachers with autistic children in their classes. Due to the way data is recorded it is not known how many of the 800 autistic pupils fall into the AS target group, but it is likely that at least 50% do not have a learning disability.

The Individual Learning Team provide intensive levels of support to students, and advice and support to their families, schools and other agencies, on occasions where their particular difficulties have brought them to a crisis point in their education. Its aim is to ensure a positive outcome at critical times for individual students. The team currently support 25 students with AS, mostly of secondary school age, on a term by term basis.

Oxfordshire has a recognised history of integrating children and young people with autism into mainstream schools with the essential autism-specific support and therapies they need. This pioneering work began in the early 1970s, even before the Baroness Warnock report recommended supported integration later that decade. Over the years, the Oxfordshire model has formed the basis for many similar services all over the country. The Autism Resource Bases are highly valued by pupils, families and staff as centres of autism expertise.

6.3.3.2 Colleges of Further Education

Abingdon & Witney College has a relatively new **AS-specialist support team**, which forms part of the Service for Autism (above) and is run by a highly experienced autism-specialist teacher. The team supports the college to enable students with AS to undertake a course of their choice, giving them the same options as their mainstream peers. This service began in September 2008 with 10 students, and now in 2010 there are 50.

Oxford & Cherwell College does not have an autism-specific support service to enable learners to access mainstream courses, but does have an **autism and AS-specialist Resource Base** at Blackbird Leys campus. The Base supports 28 students with AS, aged 16-23 years through the NOCN (National Open College Network) programme. Learning plans are individualised according to need and cover areas such as academic education, using buses, writing CVs, career planning and preparation for job seeking. Students are supported into employment and 1 has been supported into his own living accommodation.

6.3.3.3 Right employment

Right Employment currently support 4 Oxfordshire people with AS in work and 9 others to find work. They have staff experienced in this field but do not have the funding to offer a widespread service.

6.3.3.4 Restore

Restore are able to offer some employment support to those receiving a service from community mental health teams, but the person has to have a diagnosed mental health problem to access support.

6.3.3.5 Oxford Employment

Oxford Employment services offer support to people with disabilities, there was no evidence found that they were supporting anyone with AS at present.

6.3.3.6 Connexions

Connexions is a service for all young people aged 13-19 and 13-25 for those with learning difficulties, including AS. It provides information, advice and guidance on choice in learning, careers, health, relationships, sexual health, drugs, money, homelessness and more. Advisors are attached to schools or centres. There are several Connexions advisors in Oxfordshire with specific knowledge of AS, but these tend to be attached to schools or colleges catering for special needs, leaving young people with AS in mainstream schools without specialist support. Feedback suggests that a big issue for Connexions Advisors has been the lack of services and choices available for young people with AS.

6.3.4 Housing and support

Some adults with AS are being supported in accommodation where the support is paid for by OCC's social and community services and provided by different organisations with expertise in autism and learning disabilities. Some of these organisations are looking at the possibility of providing AS-specific supported living. Compared to many other client groups, existing placements are often expensive and lengthy. Feedback suggests that in some cases early diagnosis and support may have prevented the need for costly placements.

6.3.4.1 Advance shared ownership

The Advance shared ownership scheme is an innovative method of giving vulnerable people real control and choice over their housing situation and houses a small number of people with AS. However, it has limited funding (from the department of Communities and Local Government for the capital funding) for the number of places, and the method of mortgage interest payments (via welfare benefits) can be seen to discourage people from gaining full time paid employment. Shared ownership is one route to securing accommodation, but feedback suggests support should be arranged and funded separately.

6.3.4.2 Kingwood Trust

The Kingwood Trust specialises in supporting people with autism to live in their own homes and enjoy full and active lives in the community. It currently supports 1 person from Oxfordshire with a formal AS diagnosis and 5 others from within the county who staff believe would be diagnosed with AS if they were to be re-assessed in the light of current knowledge of the condition.

6.3.5 Health

6.3.5.1 OBMH

A team manager within one of the Community Mental Health Teams has become knowledgeable about this client group by dealing with several clients with AS and, from this, developing a particular interest in this field. Some care co-ordinators within OBMH have some experience of working with people with AS and have placed approximately six of these in specialist residential provision.

A greater knowledge and expertise is needed within adult mental health services in Oxfordshire. Feedback from families suggests that people with AS have been referred by GPs to teams where they have been misinterpreted, misdiagnosed and misunderstood by mental health professionals – and labelled as psychotic because of the lack of AS expertise. Examples of the consequences of this are highlighted in the stories of families told in **Appendix 7**.

In 2008, the mental health provider trust in Oxfordshire and Buckinghamshire initiated a project researching the services provided to people with AS. This involved a wide range of stakeholders and was for the whole area of the trust (i.e. Buckinghamshire as well as Oxfordshire). The project was not completed, and therefore is not included here, but the initial results of that work correlate well with those undertaken for this report and so provide a mutual level of confidence to both data sets.

6.3.5.2 CAMHS (Children and Adolescent Mental Health Services)

The Oxford CAMHS team is known to have considerable expertise and experience in AS in children and adolescents (up to age 18), but they are a very small team. Due to limited resources, they are only able to react, rather than be proactive about the services they provide. They comprise a part-time Neuro-psychiatrist, a part-time clinical specialist OT and a clinical nurse specialist. Staff rotation from one CAMHS team to another allows doctors to work in the Oxford team to gain experience in AS. However, this rotation of staff can mean that individuals with AS have to get to know different doctors working with them, which can be challenging.

6.3.5.3 The Ridgeway Partnership

Two Clinical Psychologists (one has now retired) within the Ridgeway Partnership have particular expertise and commitment to this client group, but their service criteria limits them officially to working with people with learning disabilities, with or without autism, and aged 18 or above. They have, however, considerable experience of meeting people with ASC to assess whether or not they meet the LD criteria for a service. Inevitably, they have met many people with AS this way. There is interest in AS amongst some Ridgeway Partnership psychiatrists, who are also developing expertise in this field.

6.3.5.4 GPs

As reported in the literature review, 80% of GPs told the NAO that they require more training in autism to identify and better manage patients. They also said they refer 54% of adults and 73% of older patients with undiagnosed AS to adult/older people mental health services.

6.3.5.5 Criminal Justice Services

Prison medical services and the Probation service were asked about people with AS, but it was found there was no requirement to record details or do any systematic screening. Anecdotally, a member of staff at HMP Bullingdon suggested there could be 3 people detained that have AS, and that one was difficult to manage.

6.4. Numbers currently receiving a service & costs

The tables below show summaries of services being provided to people with AS, together with the cost of these services. Our research indicates that the services identified as being currently provided to people with AS are costing in the region of £3million per year. This information is not complete due to difficulties caused by the way data is stored and other issues.

Table 1 - People with AS receiving community services directly from OBMH, as at April 2010 for the preceding 12 months

No. of clients	No. of contacts	£/contact	Total annual cost
11	277	£221.32	£61,306

Table 1- The cost per contact is based on the indicative activity prices within the current contract. One client accounted for 173 of these contacts.

Table 2 - People with AS receiving funds from the MH pooled budget

Service type	No. of clients	£/contact	Total annual cost
Residential	5	n/a	£400, 504
Support	3	n/a	£141, 024

Table 3 - People with AS known to the LD Teams⁷

Provider	No. of clients	Weekly cost	Total annual cost ⁸
Various	71	£34,521	£1,795,081

⁷ Data from Ridgeway partnership/OCC LD services

⁸ some costs are one-offs or for infrequent respite care, so some level of estimation has taken place

Table 4 - AS services provided by voluntary/private sector⁹

Provider	Service type	No. of clients	Frequency	Cost (£)
Kingwood	Accommodation	7	Ongoing	420,400
Ridgeway	Diagnostic	4	One-off	2,845
Right Employment	In work support	4	On-going	8,000
* ¹⁰ Right Employment	Employment findi	9	On-going	18,000
Children in Touch (AFS)	'Oxford Aspies' pu group	c25	Fortnightly	960
Children in Touch (AFS)	Youth groups	30	Weekly	15,115
Children in Touch (AFS)	Holiday activities	35 (aged 14-19)	Summer and Easter	5,000
Children in Touch (AFS)	Family support work	248 (incl 140 aged 1 to 17)	Ongoing but intermittent	24,500
Farleigh College of Further Education (Residential)	AS-specific supported living & support to access Mainstream college courses	7	Annual	c. 448,000

Notes:

1. Four young people with autistic spectrum conditions are in out-of-county placements funded by the education department at £109,000 pa.
2. Data from the education and CYP&F services showed that there were 81 people with Autism within these services who may need adult mental health input in the future.
3. During the research for the PCT's 'Keeping People Well' project, which is the review and re-design of mental health day services, some people identified as having AS were encountered utilising these services. This information was not specifically collected and was brought to our attention through some of the discussion groups held. There is little information on this at the present time, though people did find the activities at projects such as Restore and Bridewell Organic Gardens useful.

The data in Table 5 is from the 2009 OBMH research into service provision across their service area. Whilst the focus of this report is Oxfordshire, the Buckinghamshire data is retained for comparative and illustrative purposes. We have endeavoured to cross reference data, but due to client identification issues there may be people who are represented in more than one data set.

⁹ Grey shaded areas are duplications of the people and costs included in the OCC LD data above as some of the services funded via this route.

¹⁰ This service is partially funded from LD pooled budget

Table 5 - Adults with AS receiving statutory health or social care services across Oxfordshire and Buckinghamshire¹¹

Oxfordshire	Service provider/type	No. of clients	Weekly spend £	Annual spend £
	Ridgeway	6	1,503	78,156
	OBMH	17	1,445	75,140
	Residential placements	5	11,086	576,472
Total (Oxon)		28	14,034	729,768
Buckinghamshire	Residential placements (LD)	18	23,861	1,240,772
	Residential placements (MH)	3	7,234	376,168
	OBMH	11	2,411	125,372
	LD services	18	9,203	478,556
Total (Bucks)		50	42,709	2,220,868

6.5 Summary of findings on current provision, numbers and costs.

Our research into current provision has highlighted that there is a lack of AS-specific adult services in Oxfordshire, and provision is patchy across the county. These findings are consistent with those reported by the National Audit Office, which stated despite the need for them there is a lack of specific services in many areas.

Although there is still a great need for training and awareness amongst mainstream school staff, Oxfordshire does have a highly skilled hub of AS expertise within the education Service for Autism. This expertise is spreading to some further education colleges. Some young people with AS are able to access some social support (directly or indirectly) from CYP&F children with disabilities services. However, once young people with AS leave education or become 18 years old, there is very little support at all for them; family carers have described the effect of this as ‘falling off a cliff’.

Whilst there is no one provider in Oxfordshire with responsibility for people with AS, 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. Some of these professionals are extremely motivated.

There is little AS-specific information and social support for adults and their families in Oxfordshire, other than those provided by the voluntary sector, such as the Autistic Family Support Service – please see **Appendix 10** for details. Evidence from families and people with AS suggests 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.

Our research indicates that services currently provided to people with AS are costing around £3million per year. All parties have acknowledged that there has to be careful

¹¹ Data from the 2009 OBMH study (last updated March 2009). Data collection was not fully completed but would be expected to include the same people as are included in tables 1,2,3 & 4 except those at Farleigh College or receiving a service from AFS

planning of what services are needed in the future to ensure best use of all resources and provide opportunities for early intervention to help prevent the necessity for use of intensive services if people remain unsupported.

All of the feedback gained from teenagers and adults with AS for this report described how they wanted to be enabled to be productive, contributing members of society; and this is emphasised in the next section. The findings in this section illustrate that in order for them to achieve this, services should work in partnership to improve the knowledge they have about AS and find ways to provide a flexible, proactive and systematic approach to appropriate support.

6.6 Learning from engagement

6.6.1 Background

Six focus Groups for adults with AS and their family carers were arranged across the county in February 2010 and their comments, concerns and the issues they raised are outlined.

People with AS with their parents or carers, were identified from existing contacts, service providers and other support groups. Data was collected from 134 people around the same five themes identified by previous research by the NAS, NAO and other organisations:

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

The National Autistic Society (NAS) issued a press release, which resulted in features on BBC local radio, Banbury Sound radio, and several local newspapers across the county. A number of families not previously known to service providers responded as a result. Please see **Appendix 5** for a copy of the press release and details of dates and locations of the focus groups.

People with HFA/AS were interviewed separately from their parents/carers and a number of structured, open-ended questions were asked regarding their needs, current support and views. These are shown in **Appendix 6**, and were structured around the five key themes listed above. The results of these discussions were then analysed and the results grouped into thematic areas and priority levels.

Many attendees found the focus groups useful in themselves: to meet other people and find they weren't alone in their experiences, to gain some practical feedback or 'signposting' from the researchers and, perhaps most of all, to feel that they had been asked about their situation and their voices had been heard. The total contacts yielded from these groups is shown in Table 6 below.

Table 6 – Contact with People with AS and their Family Carers

Type of Contact	TOTALS	AS	Family Carers	Outside Target Grp	
				ASC + LD	< 14 yrs
Focus Group Meetings	98	38	57	0	3
Letters/Emails Data Collected	27	7	20	0	0
Telephone Calls Data Collected	9	3	6	0	0
Initial Enquiries, Repeat Enquiries, Anxieties/Questions By Phone & Email	201	24	147	7	23
TOTALS	335	72	230	7	26

A table showing a summary of the data collected from people with AS and their families and carers is shown in **Appendix 8**. The following sections summarise the feedback from people with AS and their family carers. Some quotes have been used below to illustrate needs, and more have been collated in **Appendix 9**.

6.6.2 Diagnosis and Support

Issues identified

Greater availability of diagnostic services – most people taking part in our research had already received a diagnosis, but 35% said there was a need for greater availability of diagnostic services. It is known that across the country many adults remain undiagnosed despite seeking help which suggests it is likely that, had we been able to reach more of the adults unknown to services, this percentage would have been a lot higher.

Diagnosis is crucial - families regarded diagnosis as crucial – many had spent years looking for answers to the problems experienced by their young people at school. A diagnosis provided the signpost to how to understand and help the person with AS. Without it, families said they did not know how to help or where to ask and professionals did not understand what they were dealing with. Without direction, families said they were left to assume that the behaviours they were faced with have social motivation, whereas the opposite is often the case and the person with AS is desperately trying to do what is being asked of them but misunderstanding what that is. Inevitably, the situation deteriorates until and unless a diagnosis results. Everyone who took part in this research had a story to tell about how being misunderstood was a problem.

“I’m 47 and received a diagnosis of HFA in 2000. I was expelled from school when I was 9 and assessed by specialists, but Asperger’s findings weren’t recognised then services for people with AS are conspicuous by their absence”

“The psychiatrist who diagnosed me left the ball in my court.....follow-up support would have helped in my case.”

Currently good in Oxfordshire

AFS was cited as offering very helpful home visits and a good information pack about autism and specialist local services. The project manager is highly respected.

6.6.3 Help in the Community and for Carers

Issues identified

Social opportunities - the adults and teenagers with AS strongly emphasised their need for more social opportunities – they feel isolated and excluded. Some people with AS wanted AS-specific social groups and activities, whilst others wanted support to access mainstream groups and activities. Activity holidays and support to access weekend and local activities were requested.

Social skills training – people with AS relayed the difficulties of social interaction; they were often the victims of bullying and were sometimes ‘conned’ out of money or possessions by people posing as friends. Misunderstandings about people and social situations were a part of everyday life for this group and many of them can be very vulnerable to predators because of their deep desire to be a part of society and to have friendships and (in many cases, but not all) sexual relationships. The support most frequently requested by parents for their son or daughter was for Social Skills Training, because everything in life hinges on whether or not people can get along with other people and much help was needed in learning about the social aspects of daily living.

Support with financial issues - the need for support for people with AS to claim benefits and understand finances generally was another area of difficulty raised as a big issue. Like other teenagers and adults, people with AS do not want to be reliant on their parents but do need support (to very varying degrees) in daily life. A service to which they could turn when in need of information, advice and/or advocacy would be very useful. This would also help reduce stress levels in family carers. The need for AS-specific benefits advice was also raised.

Carers’ needs - parents said they needed quick diagnosis for their son/daughter, and post-diagnostic information, support and counselling for themselves and their son/daughter. These would help them cope with the pressures they live with. Many parents had been looking for answers for a long time, many years in some cases, before the diagnosis was given and much stress had been caused by the delay. Parents and other family members said they had a lot to come to terms with, but instead of having the time and space to deal with their own feelings, they were forced to try and ignore them, because they were so busy supporting their son or daughter and trying to obtain support and help for them.

Carers’ breaks – it was found carers also needed more breaks – they are often living with a quite challenging person, particularly over the adolescent period, and, over the years, become worn out and depressed. Feedback indicated sibling support and local support groups for other family carers would be enormously beneficial.

Awareness training - the need for awareness training for all – specialist and generic staff and the public - (especially those in community services, social services, staff in the criminal justice system) was highlighted and other issues raised included better communication between services and the need for a key person to co-ordinate and ensure the needs of individuals are met.

In particular, recognition of their particular strengths and needs rather than a focus on difficulties and problems, and support to achieve their potential would help immeasurably to raise self-esteem.

Support for parents with AS - parents with AS, especially mothers, are a particular group with specific support needs which are currently not recognised. AS in girls and

women is less understood, resulting in misdiagnosis and misunderstandings of mothers' difficulties

Transport - transport to access support and services is needed for both people with AS and carers.

"His support workers are dedicated, but need training in AS to fully understand his needs."

"Because he is an adult, we cannot help our (40 year old) son with finances as we have no access unless he lets us and as soon as there is a problem, he hides it. The credit crunch has, for the moment, stopped the constant letters begging him to borrow money, but letters to the bank etc could not stop them from continuing to offer loans. He does not have the financial competence to deal with all this alone."

"I am 59, just diagnosed with AS, and looking for a group for mature Aspies, perhaps recently diagnosed, to share experiences, information etc."

Currently good in Oxfordshire

Examples of helpful supports were 'Oxford Aspies' social group, Wolvercote Young People's Club (AFS) and the Guideposts Trust. Some people also successfully accessed mainstream activities.

6.6.4 Employment & Other Meaningful Activity

Issues identified

School – there were many examples given of young people not being understood at school and universal agreement that teachers and school staff need training in AS. Buddy or peer mentor schemes were requested, especially for adolescents in mainstream schools. Those with AS within the Autism Resource Bases felt supported, but some did not want to be in the same Base as people who were more severely autistic, neither did they feel they belonged in mainstream.

College – there was a range of opinion about needs at college. Job skills training for young people and training for educational staff were the most highlighted issues, along with understanding of AS issues, liaison with carers and practical support. Young people with AS would like peer support from a buddy system to help them be in the right place at the right time and to manage socially at college. Some need support to organise their course work from staff who understand their difficulties and strengths.

Connexions - staff need training in AS – most people who mentioned Connexions said they were not AS trained and not able to help their son/daughter. However, one parent said the Connexions person did understand AS, but there was very little choice of options suitable for her son.

"Our Connexions person was willing, but didn't have any idea about AS – she made unrealistic suggestions, I felt she was setting my daughter up to fail."

Work – most people said there was very little support for people with AS to seek and find employment and then keep it. Right Employment has staff experienced in this field but does not have the funding to offer a widespread service. Restore are able to offer some employment support to those receiving a service from mental health teams, but only if the

person already has mental health problem. Oxford Employment services offer support to people with disabilities, but it was unknown if they were supporting anyone with AS.

Of the participants who had finished education, most had no meaningful activity during the day, but all of them wanted to do something useful. They wanted paid employment, or if not, voluntary employment, so they could make a contribution and feel a part of society.

One man in his 30s had a PhD in Information Technology but had been unable to keep a job, despite being extremely able in his field, because he had no support with the social aspects of employment. A girl in her late teens had tried voluntary work and was more than able to do the work but unable to deal with the social demands of others, so the placement failed. AS-specific practical support at work and an AS employment agency were requested and also support for self-employment.

“I can speak about employment from my personal experience. People with AS find it difficult to find/keep a job often due to prejudices among employers/other employees.”

“My son has an engineering degree from Cambridge University but has been virtually out of work for about 20 years, only getting occasional manual work. He is receiving Jobseeker’s allowance, but also has been enabled by the bank to get a credit card debt of £10,000.”

Currently good in Oxfordshire

The Autism Resource Bases were cited as ‘a haven’ from life at mainstream school. The support and therapies received through the ARBs enables many young people to gain GCSEs and A levels, because despite being academically capable, they would not manage school life without AS-specialist support. Parents value the Bases and the autism outreach and independent learning teams and spoke of their relief once AS-specific support had been accessed.

6.6.5 Housing & Support Issues

Housing to meet individual need – most people expressed a need for a wide range of housing and support to suit the particular needs of individuals with AS.

Transition to supported living - the need for gradual transition to supported living was also highlighted. Transition from home to supported living needs to be very carefully planned. A half-way house arrangement was suggested, that young people could visit and stay in for increasing periods of time, and learn daily life skills such as cooking, laundry, budgeting, using public transport etc. Most importantly, it would help ease them from dependence on parents for all their support into independence and learning to have confidence in themselves to cope with daily living away from home.

For some, the need was for help to find a home and to organise their finances, and someone to check they are managing. Once settled, a telephone support service they could call when problems or anxieties arise might suffice. Others need more ongoing practical help with housework, paying bills, keeping up with shopping, eating well and keeping mentally and physically healthy.

“We are now in our 70s and not in good health. We feel something should be available to assist him to achieve independence before he also has to cope with being bereaved of his parents.”

“I worry about what to do if something breaks in the house – e.g. water starts leaking through the ceiling or a tap is dripping – I need someone I can phone at any time to ask about things like this. I write down the answers in my little book so I can refer to them if the same thing happens again.”

6.6.6 Health Issues

Training for health staff - the need for training of generic health professionals, particularly GPs, was raised by many.

Specialist support - the need for specialist AS input and support from Mental Health professionals was also highlighted. Some families had tried to access MH services and found that the staff at CAMHS and OBMH did not appreciate the unique problems faced by people with AS and their families and this caused even more frustration and stress, sometimes resulting in mental illness, to the families and their son/daughter. In some cases, having a person who understands AS to speak with for an hour each week would make the difference between managing and slipping into mental illness.

“Lack of services and little knowledge of autism by mental health professionals increased my son’s difficulties.”

“I am in my late 40s a year ago, I tried to get incapacity benefit. My GP shouted at me, despite me giving him a list of what was wrong (Aspie symptoms, really). He said I was an able bodied person and nothing should stop me working..... I rarely go to the GP now since I cannot cope with the one that I have”

Currently good in Oxfordshire

Private psychotherapy

“My psychotherapy is extremely supportive and I think I have changed for the better but even if it suits them, very few people can afford it!”

“I don’t know where I would be now, without the psychotherapy I had. It was a lifeline when I was truly drowning. I had to find a way of paying for it because it wasn’t available on the NHS – my GP could only offer 6 sessions of CBT. I needed, and got, specialist therapy from someone who really understood what life was like for me – such help is priceless!”

6.6.7 Summary of overarching themes from engagement

The need for AS-specific support services of all kinds, in every stage of life was highlighted by all participants. Adults and young people with AS and their family members and professionals with expertise in the field were all agreed on this point. No-one thought that an effective service could be provided without an understanding of AS.

One stop shop - Families would like a One Stop Shop for life-long information, advice and support, and a multi-disciplinary team specifically trained and experienced in AS.

Person-centred planning - they also felt that AS-specific person-centred planning was necessary, as was the careful planning of transition to adulthood and the involvement of parent/carers in planning and provision of services for their son/daughter.

Seamless transition - families and people with AS thought that a seamless support service would enable key people who have known the child and family for years to support throughout the transition to adulthood and beyond, making a huge difference to outcomes for adolescents and adults. The enormous strain of supporting their son/daughter through transition without effective help was highlighted, and parents were often offered drugs by their GPs when they asked for help.

One size does not fit all – the range of need and ability is extremely wide, and so is the range of age and preferences of people with AS in terms of services, facilities and support. Only a wide and flexible range of solutions can hope to meet the needs. Some people may need a moderate level of support for life, but others may well go on to live independently for the majority of the time, just needing to know that there is AS-specific support they can tap into when the need arises.

24 hour helpline - the availability of a 24hr telephone (or text or email, or combination) help-line was suggested as one way to reassure that help is on hand if needed – thus likely preventing anxiety from rising to panic and then to crisis.

“My son, who is now 44, is in complete denial, believing everyone else has a problem, not him. I am very concerned as to what will happen to him when I am no longer around. I am 71 and would like to see him settled somewhere where people will understand him and give him some companionship.”

“I think the main things I find difficulty with are sadness and regret about the past, misunderstandings etc a sense of failure and not living up to my potential, anger at some of the treatment I have received – I suppose grieving about the way life could have been if AS had been better understood.”

6.6.8 Summary of key messages from people with AS and their families

People with AS want to have their many abilities and strengths recognised as well as their difficulties – they want to feel understood.

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

During the course of this research, the plight of many local families was particularly moving. Examples of some of their stories are given in **Appendix 7** and illustrate why early diagnosis and AS-specific support are so very necessary.

Our research has highlighted both the lack of AS-specific services in Oxfordshire and the need for such services. This state of affairs is by no means uncommon – as reported by the National Audit Office there is a lack of such services in many areas and a great need across the country.

Service models specific to adults with AS are still in their infancy across the UK, with one of the best established services, the Liverpool Asperger Team, having begun in 2003. There are service models and examples of good practice in several areas across the country and people from those services have kindly provided us with their information, including lessons learned. This information has been collated in **Appendix 11**.

6.7 Summary of Key needs

The literature on the subject of AS needs described in this report is comprehensive and coherent, and provides a good insight into the types of issues faced by those with AS, and the key services they need. Our research locally confirms the findings of the literature, and all the findings have been collated to produce a list of key needs appropriate for Oxfordshire, these are;

Key needs identified are:

1. A clear pathway for prompt AS-specialist diagnosis, assessment and support (including clinical services) particularly in transition to adulthood.
2. Individualised support to enjoy socialising, within mainstream and AS-specific localised socialising opportunities.
3. Preparation for and support in college, employment and other meaningful activity.
4. A wide range of housing and support services and knowledge of options.
5. Support and respite for family carers, including for parents with AS.
6. One-stop shop and resource centre for AS information, advice and advocacy for all age groups.
7. AS training for all those who provide both specific and generic services, especially GPs and people working in mental health and social care

7. The Way Forward

7.1 Progress to date

This report will form the basis from which the AS Steering group can create an action plan of commissioning priorities and ensure as much as possible the responsibilities set out for Local Authorities from the National Autism Strategy are undertaken.. Oxfordshire's progress to date is set out in the table below:

Responsibilities	Oxfordshire response
A Joint commissioner/senior manager should have clear commissioning responsibility for adults with autism	Fenella Trevillion leads for AS/HFA. Ann Nursey leads for Autism and LD
A commissioning plan around services for adults with autism should be developed which reflects JSNA and all other relevant data on prevalence	The JSNA has been used, & the AS needs assessment has been drafted from which a local commissioning plan will be developed.
A local Autism Partnership Board should ideally be developed – see Appendix 3 for possible structures reflecting best practice	AS Project Steering Group established and operating effectively. Discussion to be had as to whether this transforms into a partnership board
A lead professional should be appointed to develop diagnostic and assessment services for adults with autism	To be decided
The views of adults with autism and their carers must be sought and taken into account in the development and delivery of local services	Focus groups have been held, with information collected also from telephone calls, emails and letters; consultations on draft strategy to follow
Information about the numbers of adults with autism should be recorded and shared	Awaiting National protocol. Improved recording starting with introduction of diagnosis recording on the health and social care client record systems
There must be a clear care pathway to diagnosis by 2013	Awaiting NICE guidelines and local commissioning plan; Ridgeway Partnership currently provide some ASC diagnoses locally
From June 2010, strategic planning mechanisms/processes must be in place – with meaningful representation from adults with autism and their carers	AS Project Steering Group established; Kathy Erangey, qualified expert by experience and family carer, representing carers and working with PCT and OCC on needs analysis and draft report; 3 young people with AS attend meetings to give their views; people with AS who have taken part in Focus Groups could form nucleus of an email reference group; Family members who have taken part in Focus Groups could form nucleus of reference group or email reference group.

7.2 Next Steps

Planning	<p>Workshop planned for November 5th for all involved stakeholders and service users and carers – outcomes to include:</p> <ol style="list-style-type: none">1. Update on progress2. Agree needs assessment report is broadly correct3. Discuss suggested model for way forward in light of current financial climate4. Establish next steps in developing the model and an action plan. <p>Initial Suggestions to support a future model and action plan can be found in Appendix 12, and will be useful to reference in workshop discussion groups.</p>
Process	<ol style="list-style-type: none">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:<ul style="list-style-type: none">▪ Current contract variations within 2010/11 & 2011/12;▪ Procurement re tender or any willing provider

END OF MAIN REPORT



Appendix 1: Asperger's Syndrome Characteristics by Roger Meyer

Below is a list of Asperger's Syndrome characteristics. Most have been extracted from medical diagnostic criteria, descriptions offered by medical and counseling professionals, articles by educators and from employment biographies of approximately a dozen independent-living, medically or self-diagnosed AS adults over the age of 25. While every adult occasionally manifests these characteristics, what distinguishes adults with AS is their consistency of appearance, their intensity, and the sheer number of them appearing simultaneously? Some characteristics do not apply to everyone, so persons consulting this list should not feel compelled to find them all. Adults with AS who wish to compose employment biographies for their own enlightenment and/or as contributions to research should weigh the significance of the ones they share, and have their compositions accurately reflect that impact.

Social Characteristics

- Difficulty in accepting criticism or correction
- Difficulty in offering correction or criticism without appearing harsh, pedantic or insensitive
- Difficulty in perceiving and applying unwritten social rules or protocols
- "Immature" manners
- Failure to distinguish between private and public personal care habits: i.e., brushing, public attention to skin problems, nose picking, teeth picking, ear canal cleaning, clothing arrangement
- Naïve trust in others
- Shyness
- Low or no conversational participation in group meetings or conferences
- Constant anxiety about performance and acceptance, despite recognition and commendation
- Scrupulous honesty, often expressed in an apparently disarming or inappropriate manner or setting
- Bluntness in emotional expression
- "Flat affect"
- Discomfort manipulating or "playing games" with others
- Unmodulated reaction in being manipulated, patronized, or "handled" by others
- Low to medium level of paranoia
- Low to no apparent sense of humor; bizarre sense of humor (often stemming from a "private" internal thread of humor being inserted in public conversation without preparation or warming others up to the reason for the "punchline")
- Difficulty with reciprocal displays of pleasantries and greetings
- Problems expressing empathy or comfort to/with others: sadness, condolence, congratulations, etc.
- Pouting,, ruminating, fixating on bad experiences with people or events for an inordinate length of time
- Difficulty with adopting a social mask to obscure real feelings, moods, reactions
- Using social masks inappropriately (you are "xv" while everyone else is ????)
- Abrupt and strong expression of likes and dislikes
- Rigid adherence to rules and social conventions where flexibility is desirable
- Apparent absence of relaxation, recreational, or "time out" activities

- "Serious" all the time
- Known for single-mindedness
- Flash temper
- Tantrums
- Excessive talk
- Difficulty in forming friendships and intimate relationships; difficulty in distinguishing between acquaintance and friendship
- Social isolation and intense concern for privacy
- Limited clothing preference; discomfort with formal attire or uniforms
- Preference for bland or bare environments in living arrangements
- Difficulty judging others' personal space
- Limited by intensely pursued interests
- Often perceived as "being in their own world"

Physical Manifestations

- Strong sensory sensitivities: touch and tactile sensations, sounds, lighting and colors, odors, taste
- Clumsiness
- Balance difficulties
- Difficulty in judging distances, height, depth
- Difficulty in recognizing others' faces (prosopagnosia)
- Stims (self-stimulatory behavior serving to reduce anxiety, stress, or to express pleasure)
- Self-injurious or disfiguring behaviors
- Nail-biting
- Unusual gait, stance, posture
- Gross or fine motor coordination problems
- Low apparent sexual interest
- Depression
- Anxiety
- Sleep difficulties
- Verbosity
- Difficulty expressing anger (excessive or "bottled up")
- Flat or monotone vocal expression; limited range of inflection
- Difficulty with initiating or maintaining eye contact
- Elevated voice volume during periods of stress and frustration
- Strong food preferences and aversions
- Unusual and rigidly adhered to eating behaviors
- Bad or unusual personal hygiene

Morbid (shared, dual, multiple) Diagnostic Conditions

- Learning Disability
- Attention Deficit Disorder (ADD)
- Obsessive Compulsive Disorder (OCD)
- Central Auditory Processing Disorder (CAPD)
- Hyperlexia
- Depression
- Anxiety
- Non-verbal Learning Disorder (NVLD)

- Hypertension
- Semantic Pragmatic Language Disorder
- Tourette's Syndrome
- Dysthymia

Cognitive Characteristics

- Susceptibility to distraction
- Difficulty in expressing emotions
- Resistance to or failure to respond to talk therapy
- Mental shutdown response to conflicting demands and multi-tasking
- Generalized confusion during periods of stress
- Low understanding of the reciprocal rules of conversation: interrupting, dominating, minimum participation, difficult in shifting topics, problem with initiating or terminating conversation, subject perseveration
- Insensitivity to the non-verbal cues of others (stance, posture, facial expressions)
- Perseveration best characterized by the term "bulldog tenacity"
- Literal interpretation of instructions (failure to read between the lines)
- Interpreting words and phrases literally (problem with colloquialisms, cliches, neologism, turns of phrase, common humorous expressions)
- Preference for visually oriented instruction and training
- Dependence on step-by-step learning procedures (disorientation occurs when a step is assumed, deleted, or otherwise overlooked in instruction)
- Difficulty in generalizing
- Preference for repetitive, often simple routines
- Difficulty in understanding rules for games of social entertainment
- Missing or misconstruing others' agendas, priorities, preferences
- Impulsiveness
- Compelling need to finish one task completely before starting another
- Rigid adherence to rules and routines
- Difficulty in interpreting meaning to others' activities; difficulty in drawing relationships between an activity or event and ideas
- Exquisite attention to detail, principally visual, or details which can be visualized ("Thinking in Pictures") or cognitive details (often those learned by rote)
- Concrete thinking
- Distractibility due to focus on external or internal sensations, thoughts, and/or sensory input (appearing to be in a world of one's own or day-dreaming)
- Difficulty in assessing relative importance of details (an aspect of the trees/forest problem)
- Poor judgment of when a task is finished (often attributable to perfectionism or an apparent unwillingness to follow differential standards for quality)
- Difficulty in imagining others' thoughts in a similar or identical event or circumstance that are different from one's own ("Theory of Mind" issues)
- Difficulty with organizing and sequencing (planning and execution; successful performance of tasks in a logical, functional order)
- Difficulty in assessing cause and effect relationships (behaviors and consequences)
- An apparent lack of "common sense"
- Relaxation techniques and developing recreational "release" interest may require formal instruction

- Rage, tantrum, shutdown, self-isolating reactions appearing "out of nowhere"
- Substantial hidden self-anger, anger towards others, and resentment
- Difficulty in estimating time to complete tasks
- Difficulty in learning self-monitoring techniques
- Disinclination to produce expected results in an orthodox manner
- Psychometric testing shows great deviance between verbal and performance results
- Extreme reaction to changes in routine, surroundings, people
- Stilted, pedantic conversational style ("The Professor")

Work Characteristics

Many of the manifestations found in the categories above can immediately translate into work behaviors or preferences. Here are some additional ones:

- Difficulty with "teamwork"
- Deliberate withholding of peak performance due to belief that one's best efforts may remain unrecognized, unrewarded, or appropriated by others
- Intense pride in expertise or performance, often perceived by others as "flouting behavior"
- Sarcasm, negativism, criticism
- Difficulty in accepting compliments, often responding with quizzical or self-deprecatory language
- Tendency to "lose it" during sensory overload, multitask demands, or when contradictory and confusing priorities have been set
- Difficult in starting project
- Discomfort with competition, out of scale reactions to losing
- Low motivation to perform tasks of no immediate personal interest
- Oversight or forgetting of tasks without formal reminders such as lists or schedules
- Great concern about order and appearance of personal work area
- Slow performance
- Perfectionism
- Difficult with unstructured time
- Reluctance to ask for help or seek comfort
- Excessive questions
- Low sensitivity to risks in the environment to self and/or others
- Difficulty with writing and reports
- Reliance on internal speech process to "talk" oneself through a task or procedure
- Stress, frustration and anger reaction to interruptions
- Difficulty in negotiating either in conflict situations or as a self-advocate
- Very low level of assertiveness
- Reluctance to accept positions of authority or supervision
- Strong desire to coach or mentor newcomers
- Difficulty in handling relationships with authority figures
- Often viewed as vulnerable or less able to resist harassment and badgering by others
- Punctual and conscientious
- Avoids socializing, "hanging out," or small talk on and off the job

People with AS may also have co-existing conditions, these are a few examples:

1. ADHD
 2. ADD
 3. Dyslexia
 4. Dyscalculia (problems with numbers or maths)
 5. Dyspraxia (poor co-ordination)
 6. Hypotonia (poor muscle tone)
 7. Alexithymia (poor emotional processing; inability to describe emotions verbally)
 8. Social Emotional Agnosia (body language blindness)
 9. Obsessive Personality Disorder
 10. Savant Syndrome or Savant-like abilities
 11. Speech Apraxia (problems saying what one wants to correctly)
 12. Anorexia Nervosa
-

Appendix 2:

List of publications re adults with autism and their support needs

- a) Powell, Andrew (2002) 'Taking Responsibility'; good practice guidelines for services – adults with AS, NAS
- b) Adult autism strategy research – Participant summary
- c) DH 'Service for adults with autistic spectrum conditions (ASC) – good practice advice for primary care trust and local authority commissioners 2nd April 2009
- d) DH 'Better Services for People with an Autistic Spectrum Disorder – A note clarifying current government policy and describing good practice' 16th November 2006
- e) Adults with ASC Equality Impact Assessment
- f) Foundation for People with Learning Disabilities 'The economic consequences of autism in the UK' 2007
- g) Conference notes 'Falling through the cracks – why is the outcome so poor for adults with autism?' 16th July 2009
- h) Research Autism report summary: 'Factors in maintaining employment for adults with autism or AS' July 2009
- i) OxFSN (2009) 'Transition Matters – A guide to transition to adulthood for families of young people with learning disabilities' September 2009
- j) National Audit Office (2009) 'Supporting people with autism through adulthood' 5th June 2009
- k) National Autistic Society (2003) 'Autism: Rights in Reality – how many people with autism spectrum disorders and their families are still missing out on their rights'
- l) National Autistic Society (2007) 'Autism & Independence – a guide for local authorities: enabling adults with autism spectrum disorder to achieve greater independence'
- m) National Autistic Society (2008) 'I exist – the message from adults with autism in England'
- n) External Reference Group (2009) 'Final Report of the External Reference Group for the Autism Strategy' September 2009
- o) National Autistic Society (2009) 'Good Practice in supporting adults with autism: guidance for commissioners and statutory services'
- p) National Autistic Society (2008) 'Social Care – assessment of need for adults with an autism spectrum disorder'
- q) National Autistic Society (2005, reprinted 2007) 'Employing People with Asperger Syndrome: a practical guide'
- r) Beardon, L. & Edmonds, G. (2007) 'A National report on the Needs of Adults with Asperger Syndrome'
- s) HM Government DH (2010) 'Fulfilling and rewarding lives – The strategy for adults with autism in England' 3rd March 2010 – with list of guidance relating to adults with autism
- t) HM Government DH (2010) 'A first year delivery plan' with priority actions, including the development of regional delivery plans

Appendix 3: Summary of 'First Year Delivery Plan', 2010, National strategy

The primary focus of the first year is on the setting up of the governance arrangements and structures needed to drive future change, and the development of the statutory guidance and longer-term delivery plan, both to be published, with milestones, timings and measures of success, by December 2010.

The plan identifies specific actions already being taken forward and indicates other areas in which progress is being made, particularly:

1. Improving training for frontline staff in health, social care and employment support
 - a) DH has committed £500,000 (centrally held) to the development of training materials for health and social care staff by 1 December 2010
 - b) Autism awareness training will be incorporated into training portfolios for Social and Healthcare staff
 - c) All staff in the criminal justice sector will have autism awareness training
 - d) Examples of best practice training within Health and Social Care will be published by 31st December 2010
2. Supporting adults with autism into work – considered an essential priority
 - a) All Disability Employment Advisors (DEAs) will receive autism awareness training by 1st January 2011 around the needs of adults with autism and how best to help and support them in seeking employment
 - b) This information will be available to all Job Centre Plus staff
 - c) Job Centre Plus will also run specialist courses for managers

Three key tiers of governance are being formed to oversee national delivery and monitor progress of the Autism Strategy:

4. The **Adult Autism Strategy Programme Board**, which met for the first time on 31st March 2010, will provide overall governance, and is accountable to, and chaired jointly by, The Minister for Care Services and the Director General of Adult Social Care
5. The **Delivery Group**, will report to the Programme Board, with a National Implementation Manager reporting to the Delivery Group
6. **DH Deputy Regional Directors of Social Care and Partnerships** will oversee progress on a regional level, working closely with local leads. They will produce a **regional action plan by 31st March 2011**, showing key milestones and deliverables, based on the findings of an analysis/scoping exercise

The Director of Adult Social Services (DASS) should ensure there is:

“a joint commissioner/senior manager who has a clear commissioning responsibility for adults with autism”

The first year plan says it is essential that:

- Adults with autism and their families and carers, representative organisations and professionals in the field are involved during the implementation of the autism strategy
- Clear processes for regular communication and consultation with adults with autism and their representatives must be put in place

Examples of best practice in stakeholder involvement will be identified and published by March 2011.

*The Autism Strategy was developed using the core principles of inclusivity and co-production, with extensive public consultation and the involvement of an External Reference Group on autism. In particular, it sought the views of adults with autism themselves, their families and informal carers, representative organisations and professionals working in any field who come into contact with adults with autism. **It is essential that this approach continues during the implementation of the strategy and that clear processes are put in place for regular communication and consultation with adults with autism and their representatives.***

*At both regional and local levels, we will encourage processes to be put in place to ensure that the views of adults with autism and their carers are sought and taken into account in the development and delivery of services locally. **We will identify, in consultation with key stakeholders including adults with autism and carers, examples of best practice and promulgate these by March 2011.***

Increasing awareness and understanding of autism within businesses and the public

In order to increase awareness and understanding of autism within the wider community, The Programme Board will:

- Bring forward firm proposals by Autumn 2010 for a nationwide communications campaign, delivered through stakeholders, that seeks to tackle the stigma often attached to autism
- Examine the possibility of creating a network of “Autism Ambassadors” – local volunteers who actively represent and promote the needs of adults with autism in their area - the Board will consider how such a network could operate and what resources it would need
- DWP is reviewing its campaigns and programmes, such as Employ Ability, to be completed by 1 January 2011. It will aim to identify where more successful examples of adults with autism can be included.

Pathway for diagnosis

- NICE is to set out a model care pathway to form the foundation for local commissioners to develop referral and care pathways in their areas, supported by their strategic health authority where necessary. The publication date of the NICE guideline will be confirmed shortly
- The lead professional in each area will examine existing services and act on the model pathway set out by NICE
- There is to be a clear pathway to diagnosis in every area by 2013

From diagnosis to assessments

- A diagnosis of autism will trigger the duty to assess under the NHS and Community Care Act 1990 - the strategy makes this explicit

- A diagnosis of autism will also trigger a carer's assessment
- Adults with suspected autism do not need to wait for diagnosis to request a community care assessment.

Support to live independently within the community

Making reasonable adjustments to services

- Adults with autism are covered by the Disability Discrimination Act 2005 (DDA), which means that services are required to make reasonable adjustments to meet identified needs
- By 1 January 2011, DH will publish guidance on some useful kinds of adjustments applicable to the needs of adults with autism – from physical adjustments to premises to improved communication
- The guidance will also need to be supported by ongoing training for staff across public services
- Jobcentre Plus is committed to providing support required by customers with autism using Jobcentre Plus services, and will make any required reasonable adjustments, such as finding the most suitable environment or premises for conducting work focused interviews
- Adults with autism will be offered more help when claiming benefits
- It will be allowed for a third party or advocate to complete the claim over the telephone on behalf of the customers - callers should be told that this is possible

Giving adults with autism more say in their care and support

- Suitable services and support will be developed in time to enable the right to choice and personalised services to be realised
- The Right to Control will apply to many adults with autism, giving a legal right to:
 - Be told how much support they are eligible to receive
 - Decide and agree what they want to achieve
 - Have Choice and Control over their support

Help into work

- Employment support proposals to be published shortly, with timetable for delivery
- New 'fit note' launched 6th April 2010, to say what work a person can do
- Work Choice programme to be in place 1st October 2010 and will provide specialist support
- Job Coach to be available as and when required from Job Centre Plus

Enabling local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities

Setting out the role of local government

- Local Government at the heart of innovative and better service provision
- Joint Commissioner/Senior Manager to have a clear commissioning responsibility for adults with autism
- Dept for Communities and Local Government to ensure services are joined up and tailored to specific needs

- Wide range of providers, including LAs, the NHS, community and third sector organisations
- Public to be able to drive service improvement and hold Government to account

Supporting Local Government to adapt

- Local areas to set their own priorities and guide resources
- Revenue streams to be reduced, less ring-fencing for LAs
- Guidance to be published on aligning and pooling local budgets to frontline services – e.g. joint ventures by LAs and partners
- Reports, Inspections and Assessments to be reduced and co-ordinated

Regional planning and local planning

- Regional delivery plans for adults with autism to be developed this year
- From June 2010, strategic planning mechanisms/processes to be in place – with meaningful representation from adults with autism and their carers
- Local areas to develop their own commissioning plans, having gathered the necessary data
- DH will develop an organisation self-assessment tool for local areas to evaluate/measure progress – by end December 2010
- DH will provide sample business cases for local partners to use to support the setting up of local specialist autism teams – by end December 2010
- DH is leading development of a protocol for recording and sharing information about adults with autism – to be complete by end December 2010
- Health and Social Care bodies to ensure they meet their equalities duties, especially those under Disability Discrimination Act

Developing local governance structures

- The value of establishing a Local Autism Partnership Board, bringing together different organisations, services and stakeholders and setting a clear direction for improved services is highlighted. See Appendix 4 for details of four different examples of structures which have worked in these areas:
 - Cornwall Autism Partnership
 - Autism Partnership Board – Gloucestershire
 - Autism Services Development Groups and the Greater Manchester Autism Consortium
 - North East Autism Consortium (NEAC)

Appendix 4:

Autism Partnership Boards – four different examples of structures which have worked

Cornwall Autism Partnership

The Cornwall Autism Partnership (CAP) was set up to develop better support for people with autism across Cornwall. The CAP enables more effective joint planning of services for people with autism through collaboration between the local Department of Adult Social Care, Cornwall PCT, and Cornwall Children, Schools and Families Directorate. The CAP also links in with other trusts and partnership boards including those focusing on learning disabilities, mental health, children and young people, carers and transitions. The joint commissioner with responsibility for autism chairs planning meetings at least every quarter. Attendees include leads from mental health, learning disability, children and young people, Connexions, and housing.

Autism Partnership Board – Gloucestershire

The Gloucestershire Autism Partnership Board was set up in 2006. It meets quarterly to discuss and identify the needs of people with autism in the area, and to help plan the development of local services. The group consists of senior commissioners, housing representatives, Connexions and other professionals as well as adults with autism, their families and carers and local voluntary groups. A key focus of the Board is to work with mainstream agencies in order to develop better support for adults with autism. The Board is also looking to develop autism specific services.

Autism Services Development Groups and the Greater Manchester Autism Consortium

The Greater Manchester Autism Consortium has been running for over ten years. It is based on a very localised model: every local authority in the consortium has set up a multi-agency Autism Services Development Group (ASDG) consisting of representatives from all statutory agencies, parents and carers, and, in some cases, adults with autism. The chair of each local group is on the consortium steering group. The individual groups look at what can be achieved in the local area by improving current provision within resources, and by better informing the commissioning process. The consortium also funds the NAS's Family Services Development Project, which provides information, advice and support to families across Greater Manchester. Data from this project is then fed back to inform the commissioning process.

North East Autism Consortium (NEAC)

The North East Autism Consortium was established in 2006 to develop a regional approach to addressing the planning and service needs of adults with autism. In particular, it is working towards the development of a regional commissioning strategy and addresses the lack of integration with service provision across health and social care. Four service development groups have been established in the region, each tackling a specific area of services.

January, 2010

Local people with autism urged to have their say

Local people affected by Asperger syndrome or high functioning autism are being invited to have their say on autism services in Oxfordshire at a series of focus groups being held in February.

The aim of the focus groups is to find out what services are needed to better support people with Asperger syndrome or high functioning autism in the county. A steering group, set up by Oxfordshire PCT and Oxfordshire County Council Social & Community Services and consisting of commissioners, senior managers and clinicians from the PCT and the county council, as well as representatives from Autism Oxford, The National Autistic Society (NAS) and Autism Family Support, will report back to the council who will use the information when planning future autism services.

Kathy Erangey, Autism Oxford, said: "As the mum of a young man with Asperger syndrome I want to prepare my son for life as an adult so that, as far as is possible, he lives the life he wants to. This preparation includes putting him in touch with support services designed to meet his particular needs. At the moment few dedicated services are available locally, as people with Asperger syndrome or high functioning autism often fall between current learning disability and mental health services, so I know that there are many other families who are also seeking this support."

Rachel Pike, NAS regional co-ordinator, said; "It's incredibly important that people affected by autism have a voice in local government planning. The information gathered during these focus groups will be used to feedback to the local authority, service planners and providers to help ensure adults with autism receive appropriate support that enables them to lead fulfilling lives. Autism is a serious, lifelong and disabling condition, but the right support at the right time can make an enormous difference."

The Government's Adult Autism Strategy for England, which is due to be published in the February, aims to address the barriers which leave people with the condition

feeling isolated, ignored and unable to get the help they so desperately need. The strategy will look at five key areas: social inclusion, health, employment, training and choice and control. Local authorities will need to show they are addressing the needs of adults in their areas. The strategy is a direct result of the NAS / *Exist* report, which found that found at least 1 in 3 adults with autism are experiencing serious mental health difficulties due to a lack of help.

There are five local focus groups are taking place:

Tuesday 9 th February	10am –12 Midday	East Oxford Health Centre Manzil Way Cowley Oxford OX4 1XD
Tuesday 9 th February	7 – 9pm	Jubilee House 5510 John Smith Drive Cowley Oxford OX4 2LH
Wednesday 10 th February	7 – 9pm	Chinnor Village Centre High Street Chinnor OX39 4DH
Tuesday 16 th February	7 – 9pm	The Sunshine Centre 186 Edmunds Road Banbury OX16 0PJ
Tuesday 23 rd February	7 – 9pm	Corn Exchange Market Square Witney OX8 6AB

If you are an individual aged 14 or over with Asperger syndrome or high functioning autism, or a parent or carer and would like to attend please contact Kathy on kathryn@autismoxford.org.uk or 01844 353292.

For interviews and further information please contact Alice Ridley in the NAS Press Office on 020 7923 5769 or email alice.ridley@nas.org.uk

**Focus Group Questions
For Teenagers (14 years and over) and Adults with Autism and no accompanying
Learning Disability and their Family Carers**

Thank you for agreeing to help us to gather the information needed by Commissioners in Oxfordshire NHS and Oxfordshire County Council Social and Healthcare. They need this information to plan services to improve the lives of teenagers and adults with Asperger's Syndrome or high functioning autism.

The questions here are on five themes which have been identified as important for adults and teenagers with an ASC in research for the Government.

We have used the same themes and questions as Opinion Leader used in their research for the Government's consultation in 2009.

We would very much like you to come to one of our Focus Group meetings to give your views on these questions, but if you find meetings difficult, please email or post your answers to us by the end of February 2010. Please contact me if you have questions or worries about these questions or the Focus Group meetings.

Kathy

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Email: kathryn@autismoxford.org.uk



Theme 1 - Diagnosis and support

Explanation of the theme

Helping people to **find out** when someone has an ASC (autistic spectrum condition) so that they can get the help they need. This includes formal diagnosis and being sent to a professional to get a diagnosis.


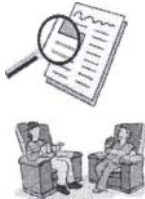

The people who **should help** to find out if they have an ASC include:

- GPs
- Staff at school and colleges
- Employers/employment agencies
- Health and social care professionals including those working in mental health and learning disability services

Staff working in charities and other community organisations

After being diagnosed people should be able to receive support

There are a number of things that might help to **improve** diagnosis and support for teenagers and adults with an ASC

<p>Increasing the awareness of an ASC amongst professionals, so they are</p> <ul style="list-style-type: none"> - able to tell if someone may have an ASC - aware of the range of autistic spectrum conditions 	
<p>Having a locally or nationally agreed set of steps (pathway) for getting a diagnosis so that professionals work together with the adult concerned and the adult knows what is going to happen in the process</p> <p>Making sure a range of professionals, for example GPs and social workers, work together</p>	
<p>Having a plan for how people affected by an ASC receive help and support after they are told they have an ASC which would include:</p> <ul style="list-style-type: none"> - emotional and practical support - help with benefits and understanding the benefits system - identifying a key worker 	
<p>Making sure that adults and teenagers with an ASC and their family (if appropriate) are involved in all of the decisions which affect them</p>	

Questions

Thinking about what you have just read, are these the most important things to improve? If not, what do you think needs to be improved?

Thinking about what you have just read, is this happening in your local area? If not what do you think needs to be done to make this happen? E.g. how would services need to change?

Theme 2 – Help in the community





Explanation of the theme





Ensuring that teenagers and adults with an ASC (autistic spectrum conditions) can **get the help they need** to be **part of the community**, do things in their free time and make friends if they want to. This also includes help with travelling and transport.

This will affect the following services:

- Social care
- Police and criminal justice system
- Leisure services
- Services which provide activities for people with an ASC
- Transport services

There are a number of things that might help to improve this issue for teenagers and adults with an ASC

<p>Making sure that people like social workers, police officers, transport and leisure workers have training on the needs of teenagers and adults with an ASC</p>	
<p>Having a plan for each teenager and adult with an ASC (person-centred planning) because:</p> <p>Teenagers and Adults with an ASC can have very different social care needs</p> <p>Adults and teenagers with an ASC need services which meet these different needs</p> <p>Making sure that services are made available throughout people's lives (especially when young people start using adult services)</p>	
<p>Helping adults and teenagers with an ASC to meet and communicate with other people by, for example, offering training in communication skills and access to social groups</p> <p>And helping adults and teenagers with an ASC to make friends if they want to</p>	
<p>Making it easier to find an advocate, someone to speak up for the person with an ASC</p>	

<p>Making sure that teenagers and adults with an ASC are able to get the right kind of support which is suitable for their needs e.g. personal assistants, social workers, advocates, etc</p>	
<p>Providing adults and teenagers with an ASC with the money to buy the services that they need as part of a personal budget</p>	
<p>Finding out about the needs of carers and supporting them</p> <p>Offering respite care to carers</p>	
<p>Making sure that there are plans made and services available when people move from children's services to adult services</p>	
<p>Helping adults and teenagers with an ASC to access the things they want to do in their spare time</p>	
<p>Making sure that teenagers and adults with an ASC and their family (if appropriate) are involved in all of the decisions which affect them</p>	

Questions

Thinking about what you have just read, are these the most important things to improve? If not, what do you think needs to be improved?

Thinking about what you have just read, is this happening in your local area? If not what do you think needs to be done to make this happen? E.g. how would services need to change?

Theme 3 - Employment and other meaningful activity





Meaningful structured activity - regular day-time activities, social enterprises, training, and education, voluntary and paid employment

Explanation of the theme

Ensuring that teenagers and adults with an ASC (autistic spectrum conditions) are able to do **regular activities** which they enjoy and help them **feel good about themselves**, for example helping other people in the community or paid employment.

Activities could include: working in **social enterprises, undertaking training and education, and having voluntary and/or paid employment**

There are a number of things that might help to improve this issue for adults and teenagers with an ASC

<p>Greater availability of activities that adults and teenagers with ASC want to do:</p> <ul style="list-style-type: none"> - Structured regular day-time activities e.g. social enterprises where people help run a business e.g. a cafe, day centres - training courses to prepare for work - creative art and craft activities - work placements - college courses - voluntary work - paid work 	
<p>More help for teenagers and adults with an ASC to find work or activities which are right for them including:</p> <ul style="list-style-type: none"> - careers advice - interview skills training (for jobs) - help to use public transport - making interviews more suited to people with an ASC - training for people who will be around people with an ASC e.g. employers, staff such as day centre staff, other employees, other students 	
<p>Making sure that teenagers and adults with an ASC get the support they need to stay in education, training or work including:</p> <ul style="list-style-type: none"> - regular and ongoing support, both formal and informal e.g. a buddy - making changes to the work area or course structure (e.g. distance learning/support to meet deadlines/ taking into account sensory issues e.g. lighting, noise levels) - helping people be more motivated 	
<p>Making sure that teenagers and adults with an ASC and their family (if appropriate) are involved in all of the decisions which affect them</p>	

Questions

Thinking about what you have just read, are these the most important things to improve? If not, what do you think needs to be improved?

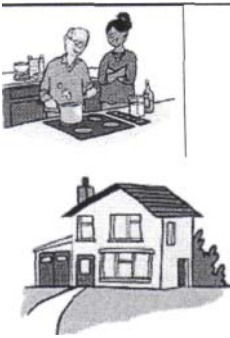



Thinking about what you have just read, is this happening in your local area? If not what do you think needs to be done to make this happen? E.g. how would services need to change?

Theme 4 - Housing and support

Explanation of the theme

Ensuring that adults with an ASC (autistic spectrum condition) are able to get the **right housing and support** to live as independently as they want

There are a number of things that might help to improve this issue for adults with an ASC

<p>Making sure that adults with an ASC are able to get housing which meets their needs so that they can live as independently as possible</p> <p>The following could help to make this possible</p> <ul style="list-style-type: none"> - a range of housing e.g. residential care and supported housing - making sure the home is suitable and does not cause problems due to sensory overload or deficit - making sure that long term funding is available to pay for the housing - making sure that there are as few new people to get to know as possible (consistent staff) 	
<p>Making sure that support workers are trained to work with adults with an ASC</p>	
<p>Making sure that adults with an ASC are able to get help if there is a crisis, for example, if they are disturbed by neighbours or they have disagreements with landlords</p>	
<p>Making sure that adults with an ASC and their family (if appropriate) are involved in all of the decisions which affect them in supported living.</p> <p>This could include:</p> <ul style="list-style-type: none"> - choice over the people caring for them - choice over the people they live with 	

Questions

Thinking about what you have just read, are these the most important things to improve? If not, what do you think needs to be improved?

Thinking about what you have just read, is this happening in your local area? If not what do you think needs to be done to make this happen? E.g. how would services need to change?




Theme 5 - Health

Explanation of the theme

Ensuring that adults and teenagers with an ASC (autistic spectrum conditions) are able to get the **healthcare that they need**. This includes:

- GPs
- Mental health doctors and nurses
- Doctors and nurses in hospitals
- Other health professionals in the community e.g. dentists, opticians, physiotherapists etc

There are a number of things that might help to improve this issue for adults and teenagers with an ASC

<p>Teenagers and adults with an ASC do not always have their health needs picked up by health professionals. This can be because of difficulties with communication.</p> <p>Like everyone else, adults and teenagers with an ASC have a range of health needs and they need support to meet their needs. The following could help to meet the needs of adults and teenagers with an ASC:</p> <ul style="list-style-type: none"> - Providing a person centred plan which covers all of the person's health needs - More specialists in an ASC available locally - Treatment for the person's entire health needs 	
<p>Making sure that healthcare professionals are trained about the needs of people with an ASC</p>	
<p>Making it easier for adults with an ASC to receive treatment, for example:</p> <ul style="list-style-type: none"> - home visits by GP - changes to waiting areas 	

<ul style="list-style-type: none"> - more flexibility around appointments 	
<p>Making sure that adults and teenagers with an ASC who also have a mental health condition receive appropriate treatment</p> <ul style="list-style-type: none"> - treating the cause of the mental health problem rather than the symptoms - being able to see mental health professionals who are experienced in helping people with an ASC - working with other professionals in a team to treat people with an ASC 	



Appendix 7: Six Families in Oxfordshire – their stories

During the course of this research, the plight of many local families was particularly moving. Brief details of some of their stories are given here to illustrate why early diagnosis and post-diagnostic support are so very necessary and what services might have helped – or are needed now to help. More families in Oxfordshire have similar needs to those illustrated below. These are not one-off situations, nor do they illustrate the full range of circumstances and needs of local families:

Family 1: A 42 year old man, sectioned since 1998

He enjoyed primary school but at secondary school was isolated, bullied, anxious – regarded as ‘unfocussed rather than unintelligent’. He had social problems at college and didn’t get the grades he was academically capable of. He became depressed and started drinking heavily on occasions, spending a lot of time lying on his bed at home. Two youth training placements did not work out.

Aged 17, he attempted suicide and was referred to an adolescent mental health hospital unit, where he was thought to have ‘early psychotic illness’. He was discharged and put under the care of a CMHT. His GP gave him injections which caused side effects.

Aged 21, his family took him to the GP and he was considered by a Consultant Psychiatrist to have early signs of schizophrenia (historically a common mis-diagnosis for ASC). For the next 9 years, he was at home, on medication and eventually was admitted to mental hospital following an assault. In the following years, he was kept as an in-patient and assaulted people on many occasions.

Some 20 years after his first suicide attempt, the question of AS was raised and two years after that, he was diagnosed. He does not need to be in the hospital placement he is in now, but there is no more suitable placement available.

This case is clearly tragic for the man and his family and also an example of the way enormous amounts of money may be spent unnecessarily and ineffectually.

Family 2: A successful career woman, needing support now

Despite seeking answers for many years to why she felt ‘different’, she remains undiagnosed, although she knows now that she has AS. She has had a very successful career, is married, with 2 children, one diagnosed with AS, the other suspected to have AS. Her husband is gravely ill. Her diagnosed son needed help, but she found it very hard to access appropriate professionals within CAMHS to get her son’s needs met. Due to significant difficulties it was deemed necessary to prescribe medication, to which her son had a severe reaction and he became very unwell.

A social worker was allocated to undertake an assessment of the family’s needs. The social worker had no experience of AS and was unable to understand the nature of comments the mother made. She felt further isolated from the support she needed.

To the mother, it appeared to be about child protection rather than the original intention of support for her and her family.

The mother was terrified that her children would be taken into care. She was unable to share her feeling that she had AS for fear it would be used against her. She did not understand the system, and had no dedicated support for herself as a parent.

The mother says:

“The worst thing about denying being AS is that I am denying what I and my children are I am one of the AS successes. I want to be able to be proud of that and be able to sing it from the trees there are actually benefits to AS!

Diagnosis and appropriate support for this woman would very likely have made a big difference as she became a wife and mother. A lot of things might have happened differently. As an adult with AS, she would greatly benefit from specialist support as she continues her parenting role, and cares for her gravely ill husband. People within the mental health team support her as best they can, but this is not their role and they are unable to adequately meet her needs.

This woman would like a befriending service for her sons. She would like a direct payment to pay someone to help with care when she goes on trips with the children. She would also greatly appreciate help with housework, e.g. an ironing service. Any support she has must be flexible and on her terms, to fit with the needs of the family. Training in AS for the assessment team social worker could have saved distress to a mother already struggling and under pressure. Training in AS, and working with families affected by AS, would have helped in the way some professionals dealt with the family. It is unfair to staff as well as to families that they should be allocated to assess and work with AS needs without appropriate training.

Family 3: A man in his 30s, needing support now

He is depressed, at home all the time, no friends, socially isolated, nothing to do, bored. He took an overdose 10 years ago and as a result an OT would meet him in a cafe for 30 minutes. He liked this because she was a good-looking young woman, but he misread her intentions and the arrangement stopped. No other services were put in place. He used to attend a gym with MH services but this stopped because they decided that, despite his depression, he did not fall within their remit.

This man should have a needs assessment, and AS-specific support services to meet his needs. He may also need psychological intervention. Perhaps he could be helped by someone able to visit the home, build up trust and help re-introduce him to the community. When he is ready, an AS-specific supported employment service could transform his life, and that of his family.

Family 4: A man in his 40s, living with his desperate, elderly mother

Living at home with his elderly mother, this man has not worked for 20 years, despite being highly qualified. He is in denial about his AS and very difficult to live with. He is

gravely in debt and his mother says she is at her wits' end, not knowing which way to turn. She says he has taken over the house and life is intolerable.

A proper assessment of his needs, by a specialist with training and expertise in AS is needed. Appropriate services might include AS-specific psychotherapy. Following therapy, a service to assist with the financial situation will be needed and an AS-specific employment service. He also needs appropriate housing and support as soon as possible, before his mother gives up.

Family 5: A man in his 20s, needing low-level support

Living at home, unemployed, socially isolated, lonely, he has started a social group for young people with AS in his area. He cannot afford to fund the group indefinitely and needs money to fund the venue – approximately £600 per year.

This social group is making a marked difference to him and the other young people who attend. Again, an AS-specific employment service would make a huge difference to this man and other young people attending his group.

Family 6: An 18 year old with lots of potential

Diagnosed with AS at the age of 5, this teenager attended the Autism Resource Bases in Oxfordshire. He was recognised as gifted and talented in IT, but experienced significant difficulties at secondary school and was excluded aged 12 and again at 15, at which point he left school.

Since then, he has spent most of his time in his bedroom, apart from a period in a failed placement at residential college. He has a bespoke package from the Service for Autism Independent Learning Team, which tries to support him into work experience using his interests and talent in IT. His talent and ability in IT (hardware and software) is recognised, but there are not enough opportunities for him to be motivated and fully engaged, especially in view of the difficulties he experiences with social interaction.

His family have struggled to support him over the years. They had a package of 2 hours' respite per week from Social Services, which the parents used to go out once a month but only one person has been available and suitable to spend time with the teenager. This package ended when he reached 18, because his IQ is too high for him or his family to access adult services. His mother's mental health has been affected – she has been on medication for depression on and off for many years. She has been unable to work due to needing to be almost constantly available to care for her son. The only support she has been able to access for herself has been from her friends, mothers of other AS teenagers.

This teenager struggles with social interaction to the point that he needs work that he can do on his own, not as part of a team. A specialist employment service could transform the life of this young man and his family by finding a way for him to use his talent and skills in IT – perhaps in supported self employment.

He will also need housing and support to live away from his parents, but this will need to be very carefully managed, with his family fully involved, to avoid a further failure in his life.

In the meantime, the parents and sibling of this young man need a respite service.

**Appendix 8:
Data from Focus Groups**

Assessment, Diagnosis and Post-diagnosis Support			
Needs:	Parents	AS	Total %
Greater availability of diagnostic services	21	2	35.38
Better information at diagnosis (info pack)	20	0	30.77
Post-diagnostic support for individuals and carers	16	1	26.15
Currently Good:	Parents	AS	Total %
Autism family support info pack	4	0	6.15
Person Centred Planning course via LD services	1	0	1.54

Help in the Community			
Needs:	Parents	AS	Total %
More social opportunities	19	13	18.39
Social skills training	24	7	17.81
Awareness in AS training for all (com. services, police, social services)	22	4	14.94
Better communication between services	15	0	8.62
Local support for carers	10	1	6.32
Transport availability/funding	10	1	6.32
Financial management skills	8	2	5.75
Befriending services	7	1	4.46
Sexuality issues training	6	2	4.46
Sibling support groups	5	0	2.87
Advocacy	4	1	2.87
Currently Good:	Parents	AS	Total %
Autism Family Support in general	6	0	3.45
Social opportunities provided by AFS	5	0	2.87
Use of mainstream services	4	0	2.3
NAS training	0	1	0.57

Housing and Accommodation			
Needs:	Parents	AS	Total %
Wide range of housing to suit particular needs of AS (not LD or MH)	31	4	31.82
Support package - everyday and crisis	28	6	30.91
Gradual transition into supported living, including skills teaching	18	3	19.1
Choice of who with and where live	5	5	9.1
Respite care	3	0	2.73
Staff consistency/training	3	0	2.73
Long-term funding	2	0	1.82
Financial support	0	2	1.82

Health			
Needs:	Parents	AS	Total %
Training in AS (& communicating with) for generic health professionals	23	7	37.04
Mental Health input/support (AS specific for individuals and parents)	25	2	33.33
Specialist local AS Multi-Disciplinary Team	11	0	13.58
Flexibility in general health services	6	0	7.41
Crisis/challenging behaviour support	4	0	4.94
Consistency in services	1	0	1.23
Currently Good:	Parents	AS	Total %
Private therapy	0	2	2.47

Employment			
Needs:	Parents	AS	Total %
College			
Job skills training	9	2	8.03
Training for educational staff (teachers, educational psychologists)	8	0	5.84
Buddy System	4	3	5.11
Careers advice (AS)	6	0	4.38
Understanding of AS specific issues	5	0	3.65
Liaison with carers	5	0	3.65
Practical support	4	0	2.92
Training for Connexions in AS	4	0	2.92
Availability of places and courses at college (suitable ones)	2	1	2.19
AS specific unit (not LH or ASD)	2	0	1.46
Fellow AS as mentors	1	0	0.73
Work			
Practical support at work	21	14	25.55
Employment AS advice agency	13	6	13.87
Benefits advice	10	0	7.3
Training in AS for employers	6	0	4.38
Support for self employment	2	0	1.46
Confidentiality re AS	0	2	1.46
Activities			
Activity holidays	5	0	3.65
1:1 support doing activities	1	0	0.73
Weekend activities	1	0	0.73
Local activities	1	0	0.73

Currently Good (1- off experiences)	Parents	AS	Total %
SENCO Oxford & Cherwell College ASD Unit Job Centre Disability Advisor College buddy system Abingdon & Witney AS support Farleigh College, Somerset			

Overarching Themes			
Needs:	Parents	YP AS	Total %
One stop shop for all AS services/specialist MD Team	18	0	33.34
Person-centred (i.e. AS specific) planning/services	15	0	27.78
Carer/parent working links/involvement	11	0	20.37
Support at all stages	5	0	9.26
Transition to adult services planned carefully	3	0	5.56
Name of AS service important (Not Asperger, Ld or MH)	1	0	1.85

Appendix 9:

Quotes from Oxfordshire people with AS and their families, from research for this project (bold type is used to separate the quotes rather than give emphasis).

"I have a son with AS, he is 30. He does not have any services whatsoever. He is bored, stops at home, has no friends and drives us mad. Every service I look at is not designed for his needs – if he can't mix with people and has all these hangs ups, I can't see how. He does not like to think he has the condition, so I am at a loss to see how I could help him to access anything which he feels stigmatizes him."

"We need more respite to reduce stress – teenagers are a pain, even without AS needs – they need to go out and do things without their parents, ours don't get those same opportunities to be independent."

"My son needs friends who do not take advantage of him or bully him."

"An advocate scheme would be very beneficial to enable people with communication difficulties (which might only become apparent when under stress)."

"..... so parenting a child when you are undiagnosed {with AS} has a lot of problems too – and the social difficulties intensify (when trying to get support from professionals who don't understand AS)"

"When I was young, sibling opportunities were very limited, and probably still are a group for siblings would be beneficial; even if AS were not mentioned, I see it as a good opportunity for children and teenagers to be social away from the environment at home with other siblings who appreciate how hard it is to be living with AS. When you're a sibling, AS isn't always the first thing you want to discuss!"

"The police don't seem to have a clue how to deal with someone with AS."

"Trying to lead a responsible working life and deal with a 'special' child/young person and also keep his sibling and elderly grandparents happy has been an enormous strain over the years – I'm now suffering from depression myself."

"Assessment and work preparation/training services are needed locally, in the same county, at least."

"My son requires help with finding, and support with keeping, employment – from an AS-specific agency."

"Our son was employed for 12 years, after a Youth Training Scheme. After being promoted beyond his emotional ability (he has enough intellectual ability to achieve much more advanced – and better paid! – employment than his AS will permit), he had a breakdown."

"Help with finding suitable useful work would have been immensely helpful when he dropped out of Uni, but three years on, he is in no fit state to work, wishing himself dead and starving himself."

"Our 39 year old son could not live alone without some support as he has several times in his life been vulnerable to predatory people who have persuaded him out of substantial amounts

of money. He also hates forms and panics over official letters, hiding them rather than asking advice.”

“Housing with a degree of support (needed by daughter).. the current floating support service would not be adequate she would need much more on hands support than they currently offer.”

“If I had the means, which I do not, I’d pay for my son to attend some of the centres that I read about where people with AS are taught to ‘practise’ living skills.

“My son lives in his head because it’s a nicer place to be than a world where he feels so vulnerable and insecure.”

“Any application for alternative accommodation has to be instigated by my son as he is an adult. My doctor suggested that ‘you have to be cruel to be kind’, i.e. tell him to leave home and find somewhere else to live. I cannot do this, even though I feel he has taken over the house and life is intolerable. I am at my wits’ end and do not know which way to turn – is there nobody about who can advise me or who can get through to him?”

“He (our son) and we also need information regarding benefits and housing, since he needs a certain amount of supervision but also needs freedom from parental oversight.”

“My GP had no expertise in autism, I think that local practices should have someone in-house with expertise in autism, due to increasing numbers being diagnosed”

“Specialised unit for challenging behaviour or breakdown, rather than the distressing environment of a mental health hospital – other disability MH have them, so we should too!”

“It seems to take a long time to get any help. We did have a GP visit last year when I was very worried, but I had to be very forceful and insist. My son refuses to go to the doctor, dentist etc.”

Appendix 10: Autism Family Support Services

The Autism Family Support Project Supporting Families & Developing Services across Oxfordshire Leaflet can be downloaded from the Talking Health pages separately

Appendix 11: Service Models in Other Areas

Service models specific to adults with AS are still in their infancy across the UK, with one of the best established services, the Liverpool Asperger Team, having begun in 2003. There are service models and examples of good practice in several areas and people from those services have kindly provided us with information, including lessons learned, which has been collated here (in alphabetical order of location):

Hertfordshire Asperger's Syndrome Services

- Training delivered to range of staff from adult social care, provider organisations, and carers over a 4/5 year period
- 5 days' AS training for 96 staff **cost £53,371**. Following the training:
- 12 people with AS in residential placements were reviewed, and
- 5 moved - 4 to lower levels of supported living arrangements; 1 to independence
- Costs reduced by £89,000 pa.
- Total savings of £250,000 from the £1m pa cost of these 12 people over 2 years
- An Asperger's social group was established

Liverpool Asperger Team

- 2001 steering group formalised; 2003 recruitment
- Established 5 years, seen some 500 people, evaluating at present (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
- Also:
- Psychologist
- Consultant Psychiatrist (1 session per month)
- Consultant Psychiatrist (1 session per week)
- Registrars on elective placement
- Trainee Psychologists

Offering:

- Assessment & Diagnosis (initially from outside of the team)
- Person Centred Approach
- Specialist knowledge, information & advice
- Awareness training
- Clinical Interventions

Lessons learned since start-up of service/Limitations of service

- Need diagnostic service within the team, not wait for outside referral
- Need more support workers
- Need forensic input for offenders
- Need building (e.g. as per Edinburgh No 6) for AS people to come to for

social activities, therapy, courses, etc & as drop in centre, base for other activities

Gloucestershire

- Joint Commissioner MH – lead on Autism - made commitment to set up service
- Joint funded post Autism Co-ordinator by NAS & Glocs CC
- Need an identified Team for AS services to sit within – Physical Disability
- Training – all Social Workers to have basic awareness training plus 2 from each team have further training – being done by NAS

Edinburgh No 6

- One stop shop HFA/AS 16+
- Funding criteria includes prevention of need for critical intervention – this has been achieved
- Service provided by Autism Initiatives UK, a charity which is able to raise additional funds for the service
- Statutory clinicians 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

Evaluation report:

- From 2005-07, over 4,000 enquiries, services used 10,000 times (by Aspies [9,000], families, professionals, other providers), 750 attended training events
- In May 2007, 258 people using services
- Targets met – including no need for critical intervention

Northamptonshire

- NAS employment service
- Widespread coverage across the county
- 'Moving On' 2 year programme – contact starts 9 months before leaving school
- Year 1 – social behaviour, communication skills, college environment
- Year 2 – at college, led by tutors, supported by NAS service
- Running 4 years (2010), funding for next 2 years agreed
- Large Resource Centre with AS/HFA/ASD activities – day, eve, weekends
- IT courses, cooking, cleaning, shopping, daily living skills
- 30+ voluntary work placements
- Some in paid work
- Consultants to employers
- Preparation for work courses
- AS support network established, similar to Face Book but moderated
- E-befriending and website
- Also other AS support services provided by NAS
- Extensive outreach team – from support to go for a meal to 24hr support
- Community houses – 12 – with 90 clients
- Residential home – 6 people complex AS unit for people coming out of secure hospital

Nottinghamshire Adults with Asperger's Team

- Social Care focus, with a vision to become a multi-agency team
- Team based in Mansfield, within Nottinghamshire Adult Social Care & Health Dept
- Nottinghamshire, excluding Nottingham City, Pop 650,000, estimated number with AS: 2,192
- Initiated from Commissioning Strategy for people with AS 2007 - 2009, prompted by a lot of people coming through from children's services:
www.nottinghamshire.gov.uk/comstrataspergers.pdf
- Initial Funding: £140k pa from the county council, and £200k pa from PCT
- 2010/11 Funding: £225k – Social Care Component + £100k for Psychology, Psychiatry, Occupational Therapy, Speech and Language Therapy
- Team consists of 1 Team Manager, 2 Social Workers, 2 Community Care Officers, 1 part time Care Manager and 1 administrator.
- FACS – Nottinghamshire moved to: 'moderate' risk to independence
- Workload: 180 referrals in 2009, averaging 3 new ones per week, 20 redirected elsewhere. In 2010, providing care for 130 people
- Open-access Referrals also accepted where diagnosis suspected/being sought
- Groundbreaking website for adults with AS launched 2010, adults with AS helped to plan and test the site: www.aspergers.nottsinfoscript.co.uk

Lessons learned since start-up of service/Limitations of service

- Diagnostic service is essential – in 2010, 50 outstanding diagnostic assessments
- No infrastructure of services compared to LD, e.g. Supported Living Co-ordinator, Adult Placement Scheme, Variety of Support Services, Dedicated Assessment/therapeutic supports
- Pressure on service to immediately be seen as 'experts' – this develops over time
- Large geography
- Changed expenditure codes to differentiate between LD/Autism/Aspergers – very helpful
- Have evidenced that small(ish) packages work
- Have Aspergers presence at all commissioning and service groups, including: Housing Strategy, Employment, SDS/PPF, Market management, Training and Development, Welfare Rights
- Clearly not 'there' yet – service not driven sufficiently by people with AS or their carers, but services are being delivered which are valued

Warwickshire: Locality Based Service Broker Service for Adults with ASC

- AS-specific support worker post created in 2009 within team for the elderly, to allow those assessed as not meeting FACS criteria to be supported
- Funding: Salary scale 5 (22-25) £19,370 – £21,244
- Second support worker just recruited (2010)
- Third support worker post for 15-19 year olds, to be funded by childrens' services, being planned
- Caseload: 37 plus 8 on waiting list (June 2010)
- Some clients found to meet FACS criteria as support worker got to know them. In those cases, support worker clearly identifies FACS eligible needs and refers clients back to LD teams for this work (e.g. housing needs), but clients also remain with AS support worker for specific, focussed work, ensuring clients are not left without a service whilst waiting for LD teams to pick up cases (a lesson

learned)

- If regular, ongoing, paid support is needed, the FACS teams provide this
- Open referral system, including self-referral
- When focussed work completed, clients keep in touch with support worker & they can re-refer themselves if needed.
- Every child with ASC known to AS support service from 1st year onwards, to aid planning – very good administrator/organiser has responsibility for records
- Warwickshire has no transition team – it has a lead in CYP&F and one in adult services with responsibility to liaise with each other for all disabilities, but not for mental health. Budget is for 2 years transition work (assessment planning & decision over who takes responsibility in adult services)
- 2 days per week from LD specialist employment team – preparation for employment
- A lot of informal arrangements are developing

Lessons learned since start-up of service/Limitations of service

- Service originally offered to adults with AS for time-limited period – person centred, goal focussed, breaking down barriers - time limit later lifted as it was not working, now service limited by when specific goal(s) agreed with client is/are achieved
- There has been a need to be very clear about who does what and how, so as to allay staff fears about being ‘dumped on’ and to avoid defensiveness
- Several clients with goals reached now being supported by occasional text messages – this reassurance of help being there if they need it is enough to help them cope with life
- No joint working/funding with health – all from County Council
- Diagnostic and clinical services needed

Windsor & Maidenhead

- Community Team, LD services funded £10,000 research post, then a 2nd year
- New Service – 10 months old (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
- 1/6th size of Oxfordshire

Appendix 12: Suggested model of development and delivery

These initial suggestions to support a future model and action plan have been outlined below and will be useful to inform discussion at the workshop on the 5th November 2010 and then in developing a service specification of requirements.

Suggested Model of Development

The following suggestions and those in the section below are based on the Oxfordshire needs analysis and their outcomes are in line with those to be covered by the Section 7 statutory guidance to be published in December 2010. Those marked with * have already been recommended in the Year One National Autism Strategy of March 2010.

1. *The AS Project steering group, which oversaw the production of this report should become the Oxfordshire Autism Partnership Board, which should be independently chaired. Membership should be reviewed to ensure that the Board is able to impact on development of services for adults with AS across the county (See Appendix 4 for suggested membership).
2. The Autism Partnership Board should be reviewed annually in the light of legislative changes and progress made.
3. *It is vital to have meaningful engagement on the Board from people with AS and representative and voluntary groups.
4. The Board should work towards an agreed service model and draw up an action framework and a Terms of Reference.
5. *Information on the numbers of children, young people and adults with autism and AS should be collected for use in planning future service development.

Summary of Suggestions for Services

1. Diagnosis and Care Pathway

- a) *A clear care pathway to diagnostic assessment should be developed by 2013. NICE is developing a clinical guideline, to include diagnostic processes and a model care pathway for adults, which will form the foundation for local commissioners to develop referral and care pathways in their areas. The publication date for this guidance is not yet known. NICE guidance on recognition, referral and diagnosis of autism in children and young people is due for publication in September 2011.
- b) The possibility of setting up an AS specific team could be investigated when the financial climate improves. Models of good practice nationally have been developed in Liverpool and Nottingham
- c) The care pathway could incorporate:
 - i. An information/advice/signposting service offering AS expertise and personalised discussion and website
 - ii. Peer group meetings offering training and development around skills, such as socialising and relationships
 - iii. 1:1 Work to meet specific goals agreed individually
 - iv. An assessment service and access to diagnosis
 - v. Training of staff in, and development of, generic services

2. Help in the Community and for Carers

- a) *Support services (such as social skills groups, social opportunities, a befriending scheme, information, advice and advocacy) should be developed to be made available following diagnosis and tailored to individual needs. When people meet the Fair Access to Care Services (FACS) eligibility criteria this will be purchased through a personalised budget. Prompt diagnosis and appropriate support is likely to reduce the need for costly clinical intervention, as demonstrated by the Number 6 service in Edinburgh (see Appendix 11) and the NAO report.
- b) Low cost yet creative solutions to providing social support for adults with AS should be investigated
- c) *Following a diagnosis, all adults should be informed of their right to an assessment under the Community Care Act, and this assessment should be undertaken by people with AS expertise. Carers are also entitled to an assessment of their needs.
- d) Support and breaks for family carers of all ages should be accessible as needed, particularly for parents who have AS

3. Employment and Other Meaningful Activity

- a) AS specific information and support for 14+ should be available and support for transition from school to college or other meaningful activity tailored to individual need, with multi-agency working
- b) Support should be available to enable school leavers with AS to access the range of options open to mainstream school leavers
- c) Current good practice models within further education colleges should be shared so that all local colleges can offer AS-specific support.
- d) *AS-specific employment preparation and support services should be easily accessible.

4. Housing and Support

- a) A wide range of housing and support options should be available
- b) Commissioned housing and support services should be sensitive to the specific needs of people with AS and tailored to the needs of the individual
- c) Housing transition may be a point of anxiety for adults with AS. This process should be carefully planned and managed, taking into account individual needs.

5. Health

- a) *All current Health Services must be sensitive to the specific needs of people with AS
- b) A range of talking and other therapies, provided by professionals with AS specific expertise, should be available to people with AS and their family carers. The AS expertise of some self-employed therapists has been cited in our needs analysis as being particularly helpful. When such expertise is not available through normal channels, access should be enabled as appropriate.
- c) The administering of medications should be done by an appropriately trained individual with specialist knowledge of AS.

Possible Models of Delivery

In Oxfordshire, the current financial climate will necessarily restrict what we are able to achieve in the short term. Possibilities are listed below:

1. A central hub of AS-expertise should be established. All members of the hub service must (as one teenager puts it) 'get AS'.
 2. The AS hub service staff could act as a source of expert knowledge for other professionals in the county, improving AS understanding across Oxfordshire services.
 3. *A multi-tiered training framework should be implemented to train staff across all sectors in the county. Different levels of training could cater for differing levels of contact that professionals have with young people and adults with AS. Training could be provided through the AS hub service and/or the AS hub service could act as a point of contact for trainers from elsewhere, supported by a defined training budget.
-

**Appendix 13:
The Adult Autism Spectrum Quotient (AQ)**

The Adult Autism Spectrum Quotient (AQ)

Ages 16+

For full details, please see:

S. Baron-Cohen, S. Wheelwright, R. Skinner, J. Martin and E. Clubley, (2001)
[The Autism Spectrum Quotient \(AQ\) : Evidence from Asperger Syndrome/High Functioning Autism, Males and Females, Scientists and Mathematicians](#)
 Journal of Autism and Developmental Disorders 31:5-17

Name:..... Sex:.....

Date of birth:..... Today's Date:.....

How to fill out the questionnaire

Below are a list of statements. Please read each statement very carefully and rate how strongly you agree or disagree with it by circling your answer.

DO NOT MISS ANY STATEMENT OUT.

Examples

E1. I am willing to take risks.	definitely agree	slightly agree	slightly disagree	definitely disagree
E2. I like playing board games.	definitely agree	slightly agree	slightly disagree	definitely disagree
E3. I find learning to play musical instruments easy.	definitely agree	slightly agree	slightly disagree	definitely disagree
E4. I am fascinated by other cultures.	definitely agree	slightly agree	slightly disagree	definitely disagree

1. I prefer to do things with others rather than on my own.	definitely agree	slightly agree	slightly disagree	definitely disagree
2. I prefer to do things the same way over and over again.	definitely agree	slightly agree	slightly disagree	definitely disagree
3. If I try to imagine something, I find it very easy to create a picture in my mind.	definitely agree	slightly agree	slightly disagree	definitely disagree
4. I frequently get so strongly absorbed in one thing that I lose sight of other things.	definitely agree	slightly agree	slightly disagree	definitely disagree
5. I often notice small sounds when others do not.	definitely agree	slightly agree	slightly disagree	definitely disagree
6. I usually notice car number plates or similar strings of information.	definitely agree	slightly agree	slightly disagree	definitely disagree
7. Other people frequently tell me that what I've said is impolite, even though I think it is polite.	definitely agree	slightly agree	slightly disagree	definitely disagree
8. When I'm reading a story, I can easily imagine what the characters might look like.	definitely agree	slightly agree	slightly disagree	definitely disagree
9. I am fascinated by dates.	definitely agree	slightly agree	slightly disagree	definitely disagree
10. In a social group, I can easily keep track of several different people's conversations.	definitely agree	slightly agree	slightly disagree	definitely disagree
11. I find social situations easy.	definitely agree	slightly agree	slightly disagree	definitely disagree
12. I tend to notice details that others do not.	definitely agree	slightly agree	slightly disagree	definitely disagree
13. I would rather go to a library than a party.	definitely agree	slightly agree	slightly disagree	definitely disagree
14. I find making up stories easy.	definitely agree	slightly agree	slightly disagree	definitely disagree
15. I find myself drawn more strongly to people than to things.	definitely agree	slightly agree	slightly disagree	definitely disagree
16. I tend to have very strong interests which I get upset about if I can't pursue.	definitely agree	slightly agree	slightly disagree	definitely disagree
17. I enjoy social chit-chat.	definitely agree	slightly agree	slightly disagree	definitely disagree
18. When I talk, it isn't always easy for others to get a word in edgeways.	definitely agree	slightly agree	slightly disagree	definitely disagree
19. I am fascinated by numbers.	definitely agree	slightly agree	slightly disagree	definitely disagree

20. When I'm reading a story, I find it difficult to work out the characters' intentions.	definitely agree	slightly agree	slightly disagree	definitely disagree
21. I don't particularly enjoy reading fiction.	definitely agree	slightly agree	slightly disagree	definitely disagree
22. I find it hard to make new friends.	definitely agree	slightly agree	slightly disagree	definitely disagree
23. I notice patterns in things all the time.	definitely agree	slightly agree	slightly disagree	definitely disagree
24. I would rather go to the theatre than a museum.	definitely agree	slightly agree	slightly disagree	definitely disagree
25. It does not upset me if my daily routine is disturbed.	definitely agree	slightly agree	slightly disagree	definitely disagree
26. I frequently find that I don't know how to keep a conversation going.	definitely agree	slightly agree	slightly disagree	definitely disagree
27. I find it easy to "read between the lines" when someone is talking to me.	definitely agree	slightly agree	slightly disagree	definitely disagree
28. I usually concentrate more on the whole picture, rather than the small details.	definitely agree	slightly agree	slightly disagree	definitely disagree
29. I am not very good at remembering phone numbers.	definitely agree	slightly agree	slightly disagree	definitely disagree
30. I don't usually notice small changes in a situation, or a person's appearance.	definitely agree	slightly agree	slightly disagree	definitely disagree
31. I know how to tell if someone listening to me is getting bored.	definitely agree	slightly agree	slightly disagree	definitely disagree
32. I find it easy to do more than one thing at once.	definitely agree	slightly agree	slightly disagree	definitely disagree
33. When I talk on the phone, I'm not sure when it's my turn to speak.	definitely agree	slightly agree	slightly disagree	definitely disagree
34. I enjoy doing things spontaneously.	definitely agree	slightly agree	slightly disagree	definitely disagree
35. I am often the last to understand the point of a joke.	definitely agree	slightly agree	slightly disagree	definitely disagree
36. I find it easy to work out what someone is thinking or feeling just by looking at their face.	definitely agree	slightly agree	slightly disagree	definitely disagree
37. If there is an interruption, I can switch back to what I was doing very quickly.	definitely agree	slightly agree	slightly disagree	definitely disagree
38. I am good at social chit-chat.	definitely agree	slightly agree	slightly disagree	definitely disagree
39. People often tell me that I keep going on and on about the same thing.	definitely agree	slightly agree	slightly disagree	definitely disagree

40. When I was young, I used to enjoy playing games involving pretending with other children.	definitely agree	slightly agree	slightly disagree	definitely disagree
41. I like to collect information about categories of things (e.g. types of car, types of bird, types of train, types of plant, etc.).	definitely agree	slightly agree	slightly disagree	definitely disagree
42. I find it difficult to imagine what it would be like to be someone else.	definitely agree	slightly agree	slightly disagree	definitely disagree
43. I like to plan any activities I participate in carefully.	definitely agree	slightly agree	slightly disagree	definitely disagree
44. I enjoy social occasions.	definitely agree	slightly agree	slightly disagree	definitely disagree
45. I find it difficult to work out people's intentions.	definitely agree	slightly agree	slightly disagree	definitely disagree
46. New situations make me anxious.	definitely agree	slightly agree	slightly disagree	definitely disagree
47. I enjoy meeting new people.	definitely agree	slightly agree	slightly disagree	definitely disagree
48. I am a good diplomat.	definitely agree	slightly agree	slightly disagree	definitely disagree
49. I am not very good at remembering people's date of birth.	definitely agree	slightly agree	slightly disagree	definitely disagree
50. I find it very easy to play games with children that involve pretending.	definitely agree	slightly agree	slightly disagree	definitely disagree

**Developed by:
The Autism Research Centre
University of Cambridge**

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THE CAMBRIDGE BEHAVIOUR SCALE

Please fill in this information and then read the instructions below.

ALL INFORMATION REMAINS STRICTLY CONFIDENTIAL

Name:..... Sex:.....

Date of birth:..... Today's date:.....

How to fill out the questionnaire

Below are a list of statements. Please read each statement very carefully and rate how strongly you agree or disagree with it by circling your answer. There are no right or wrong answers, or trick questions.

IN ORDER FOR THE SCALE TO BE VALID, YOU MUST ANSWER EVERY QUESTION.

Examples

E1. I would be very upset if I couldn't listen to music every day. strongly agree slightly agree slightly disagree strongly disagree

E2. I prefer to speak to my friends on the phone rather than write letters to them. strongly agree slightly agree slightly disagree strongly disagree

E3. I have no desire to travel to different parts of the world. strongly agree slightly agree slightly disagree strongly disagree

E4. I prefer to read than to dance. strongly agree slightly agree slightly disagree strongly disagree

1. I can easily tell if someone else wants to enter a conversation.	strongly agree	slightly agree	slightly disagree	strongly disagree
2. I find it difficult to explain to others things that I understand easily, when they don't understand it first time.	strongly agree	slightly agree	slightly disagree	strongly disagree
3. I really enjoy caring for other people.	strongly agree	slightly agree	slightly disagree	strongly disagree
4. I find it hard to know what to do in a social situation.	strongly agree	slightly agree	slightly disagree	strongly disagree
5. People often tell me that I went too far in driving my point home in a discussion.	strongly agree	slightly agree	slightly disagree	strongly disagree
6. It doesn't bother me too much if I am late meeting a friend.	strongly agree	slightly agree	slightly disagree	strongly disagree
7. Friendships and relationships are just too difficult, so I tend not to bother with them.	strongly agree	slightly agree	slightly disagree	strongly disagree
8. I often find it difficult to judge if something is rude or polite.	strongly agree	slightly agree	slightly disagree	strongly disagree
9. In a conversation, I tend to focus on my own thoughts rather than on what my listener might be thinking.	strongly agree	slightly agree	slightly disagree	strongly disagree
10. When I was a child, I enjoyed cutting up worms to see what would happen.	strongly agree	slightly agree	slightly disagree	strongly disagree
11. I can pick up quickly if someone says one thing but means another.	strongly agree	slightly agree	slightly disagree	strongly disagree
12. It is hard for me to see why some things upset people so much.	strongly agree	slightly agree	slightly disagree	strongly disagree
13. I find it easy to put myself in somebody else's shoes.	strongly agree	slightly agree	slightly disagree	strongly disagree
14. I am good at predicting how someone will feel.	strongly agree	slightly agree	slightly disagree	strongly disagree

15. I am quick to spot when someone in a group is feeling awkward or uncomfortable.	strongly agree	slightly agree	slightly disagree	strongly disagree
16. If I say something that someone else is offended by, I think that that's their problem, not mine.	strongly agree	slightly agree	slightly disagree	strongly disagree
17. If anyone asked me if I liked their haircut, I would reply truthfully, even if I didn't like it.	strongly agree	slightly agree	slightly disagree	strongly disagree
18. I can't always see why someone should have felt offended by a remark.	strongly agree	slightly agree	slightly disagree	strongly disagree
19. Seeing people cry doesn't really upset me.	strongly agree	slightly agree	slightly disagree	strongly disagree
20. I am very blunt, which some people take to be rudeness, even though this is unintentional.	strongly agree	slightly agree	slightly disagree	strongly disagree
21. I don't tend to find social situations confusing.	strongly agree	slightly agree	slightly disagree	strongly disagree
22. Other people tell me I am good at understanding how they are feeling and what they are thinking.	strongly agree	slightly agree	slightly disagree	strongly disagree
23. When I talk to people, I tend to talk about their experiences rather than my own.	strongly agree	slightly agree	slightly disagree	strongly disagree
24. It upsets me to see an animal in pain.	strongly agree	slightly agree	slightly disagree	strongly disagree
25. I am able to make decisions without being influenced by people's feelings.	strongly agree	slightly agree	slightly disagree	strongly disagree
26. I can easily tell if someone else is interested or bored with what I am saying.	strongly agree	slightly agree	slightly disagree	strongly disagree
27. I get upset if I see people suffering on news programmes.	strongly agree	slightly agree	slightly disagree	strongly disagree
28. Friends usually talk to me about their problems as they say that I am very understanding.	strongly agree	slightly agree	slightly disagree	strongly disagree
29. I can sense if I am intruding, even if the other person doesn't tell me.	strongly agree	slightly agree	slightly disagree	strongly disagree
30. People sometimes tell me that I have gone too far	strongly agree	slightly agree	slightly disagree	strongly disagree

with teasing.

- | | | | | |
|---|----------------|----------------|-------------------|-------------------|
| 31. Other people often say that I am insensitive, though I don't always see why. | strongly agree | slightly agree | slightly disagree | strongly disagree |
| 32. If I see a stranger in a group, I think that it is up to them to make an effort to join in. | strongly agree | slightly agree | slightly disagree | strongly disagree |
| 33. I usually stay emotionally detached when watching a film. | strongly agree | slightly agree | slightly disagree | strongly disagree |
| 34. I can tune into how someone else feels rapidly and intuitively. | strongly agree | slightly agree | slightly disagree | strongly disagree |
| 35. I can easily work out what another person might want to talk about. | strongly agree | slightly agree | slightly disagree | strongly disagree |
| 36. I can tell if someone is masking their true emotion. | strongly agree | slightly agree | slightly disagree | strongly disagree |
| 37. I don't consciously work out the rules of social situations. | strongly agree | slightly agree | slightly disagree | strongly disagree |
| 38. I am good at predicting what someone will do. | strongly agree | slightly agree | slightly disagree | strongly disagree |
| 39. I tend to get emotionally involved with a friend's problems. | strongly agree | slightly agree | slightly disagree | strongly disagree |
| 40. I can usually appreciate the other person's viewpoint, even if I don't agree with it. | strongly agree | slightly agree | slightly disagree | strongly disagree |

Thank you for filling this questionnaire in.

END OF DOCUMENT