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1. Introduction
We are using the term AS to mean Asperger’s syndrome and other autistic spectrum conditions with no co-existing learning disability.

A consultation was held during December 2010. This included a workshop to discuss the future options for developing services for people with AS; a questionnaire to understand the views about services for people with Aspergers; and a discussion strand available via Talking Health.

2. Executive Summary

2.1 Introduction
In early 2010 a needs assessment was developed looking particularly at the needs of those with AS. This used a range of methods including identification of other research, local workshops with service users and an analysis of the current legislation and guidance. The needs assessment was published in November and gave strong indications of where local people felt there were unmet needs.

2.2 Next steps
A small pot of money was identified to try to go some way to meeting those needs. Following this a workshop was held in December to discuss how to establish priorities for the future work with this group. We also set up an online questionnaire and a discussion group to look at some of the options open for next action.

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

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

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

Pathways
The use of pathways was also discussed. Signposting should be clear and entry to the pathway should be as easy as possible. But it was also suggested that the pathway needs to be personalised for individuals and carefully crafted to recognise the particular needs of those with AS.
Family carers
The needs of family carers were important to the respondents of the questionnaire. There needs to be recognition of their expertise and effective support during transition.

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

2.4 Next steps
This report will be taken into account in the future provision of services and in future a report will be made of the changes made as a result of public input.

3. Background
In England about half of all people who have autism** also have a learning disability. A learning disability means you have an IQ below 70. People with autism and a learning disability may receive support and services from learning disability teams.

People with autism that have an average, or above average IQ, (commonly referred to as Asperger’s syndrome or high functioning autism), often find it difficult to get support for or understanding of their needs. The Autism Act, 2009 and the National Autism Strategy, 2010 say there is a lack of services for people with AS. People with AS have not had a clear route to assessment, diagnosis or support. Neither mental health teams, nor learning disability teams have supported people into services.

4. The local picture
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 public services.

The ‘Better Mental Health in Oxfordshire’ consultation identified that more services for people with AS were needed.

There is a lack of information on how many people with AS there are because of difficulties caused by:
- no diagnosis
- inaccurate record-keeping (AS data has not been needed in the past)
- some double counting

The gap between estimated national numbers of people and current service provision is wide.

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

There is only a limited amount of money and time currently available for this project to improve the care pathway for people with AS. The project will not meet all people’s needs. The project will need to make important decisions about doing the best thing.

5. National guidance

The Autism Act, 2009:
• sets out dates for the publication of guidance for local authorities about the planning and provision of services for adults on the autistic spectrum
• requires a plan for meeting the needs of adults with autistic spectrum conditions in England by improving the provision of relevant services to such adults by local authorities and NHS bodies

The national strategy ‘Fulfilling and rewarding lives’, the ‘strategy for adults with autism in England, was published in March 2010. This national strategy will be reviewed in 2013. It looks at:
• increasing awareness and understanding of autism among frontline professionals
• developing a clear, consistent pathway for diagnosis in every area, which is followed by the offer of a personalised needs AS assessment
• improving access for adults with autism to the services and support they need to live independently within the community
• helping adults with autism into work
• enabling local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities

Statutory guidance for local authorities and the NHS on the National Autism Strategy published in December 2010 says that:

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

In addition, young people with autism can expect that:
• they will receive transition support as they move from into adulthood they and their parents/carers will be informed of their right to a community care
• they and their parents will be informed of their right to a community care assessment for adult services, and their carers will be informed of their right to a carer’s assessment
• they are involved in transition planning and support and that no decision about them is made without them.

The National Autistic Society, the National Audit Office and other organisations say there are 5 themes:
1. Diagnosis and support
2. Help in the community
3. Employment and other meaningful activity
4. Housing and support
5. Health

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

6. Oxfordshire Asperger’s Syndrome Project Progress to date
The steering group has looked at the key needs and the responsibilities set out for local authorities from the National Autism Strategy.

Oxfordshire’s progress is set out below. This includes further work based on the findings of the needs Asperger’s assessment:
<table>
<thead>
<tr>
<th>Responsibilities</th>
<th>Oxfordshire</th>
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<tbody>
<tr>
<td>A Joint commissioner/ senior manager should have clear commissioning responsibility for adults with autism</td>
<td>Fenella Trevillion, NHS Oxfordshire, leads for Asperger’s syndrome and high functioning autism Ann Nursey, Oxfordshire County Council, leads for Autism and Learning disability</td>
</tr>
<tr>
<td>A commissioning plan around services for adults with autism should be developed which reflects the Joint Strategic Needs Analysis and all other relevant data on prevalence</td>
<td>A needs analysis has been completed and a report prepared, on which strategy and commissioning plan will be based.</td>
</tr>
<tr>
<td>A local Autism partnership board should ideally be developed</td>
<td>Asperger’s syndrome project steering group established and operating effectively. Discussion to be had as to whether this transforms into a partnership board</td>
</tr>
<tr>
<td>A lead professional should be appointed to develop diagnostic and Asperger’s assessment services for adults with autism</td>
<td>To be decided</td>
</tr>
<tr>
<td>The views of adults with autism and their carers must be sought and taken into account in the development and delivery of local services</td>
<td>Focus groups have been held, with information collected also from telephone calls, emails and letters; consultations on needs analysis report and strategy options undertaken</td>
</tr>
<tr>
<td>Information about the numbers of adults with autism should be recorded and shared</td>
<td>Awaiting national protocol. Improved recording starting with introduction of diagnosis recording on the health and social care client record systems</td>
</tr>
<tr>
<td>There must be a clear care pathway to diagnosis by 2013</td>
<td>Awaiting NICE guidelines and local commissioning plan; potential ways forward are being investigated and discussed</td>
</tr>
<tr>
<td>From June 2010, strategic planning mechanisms/processes must be in place – with meaningful representation from adults with autism and their carers</td>
<td>Asperger’s syndrome project steering group established; Kathy Erangey, qualified expert by experience and family carer, representing carers and working with Primary Care Trust and Oxfordshire County Council on needs analysis and draft report; young people with AS have been attending meetings to give their views; People with Asperger’s syndrome having taken part in Focus Groups could form nucleus of an email reference group; Family members having taken part in focus groups could form nucleus of reference group or email reference group</td>
</tr>
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7. The needs identified in Oxfordshire

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

The key findings from this are:

**Survey of services**
1. A lack of AS-specific adult services in Oxfordshire.
2. Not all places in Oxfordshire have services.
3. A need for training and awareness amongst main-stream school staff.
4. Oxfordshire has a highly skilled hub of AS expertise within the education service for autism.
5. This expertise is spreading to some further education colleges.
6. Some young people with AS are able to access some social support (directly or indirectly) from Oxfordshire County Council children with disabilities services.
7. Once young people with AS leave education or become 18 years old, there is very little support for them, most have none.
8. There are some professionals knowledgeable in AS amongst all of the services, but this has more to do with their special interest in this client group than having had access to professional formal training.
9. There is little AS-specific information and social support for adults and their families in Oxfordshire, other than those provided by the voluntary sector.
10. Those who have had some support from statutory services have often had to reach crisis point before being able to access it and have done so via Learning Disability or Mental Health teams.

**Focus group work**
1. People with AS want to be enabled to go to college and to work
2. People with AS want to socialise, make friends and have relationships
3. A key worker/person is needed to ensure the person gets services and these are co-ordinated
4. Good communication between education, health, mental health and social care departments is essential
5. Adolescent years are crucial – at the very time the need for consistent and effective support is greatest, the staff and/or services change or disappear. Transition to adulthood is enough to cope with, transition to different support service staff and set ups is an unnecessary extra burden to young people and their families.
6. Connexions service is aimed at people with AS during the transition period, but many families reported it did not help their young person with AS. Only 2 Connexions advisors with understanding about AS were identified across Oxfordshire by families.
7. A one-stop shop for advice, information, support and advocacy is needed – information is hard to access and services so disjointed that people do not know where to start or what exists.
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.

8. Consultation summary

There were three parts to the consultation. A workshop took place on Friday 10 December 2010. Over 100 people – a mix of professionals those with AS and family carers – were invited and 68 attended. A survey was also available online and on paper for completion and an online discussion group was set up.

In all over 500 people (either known to us or registered on Talking Health) were invited to get involved in this consultation and in addition the Local Involvement Networks membership were invited to take part. Those attending the workshop were encouraged to register on Talking Health and in total 91 registered on the site – this included some who were not invited to the workshop but had a registered interest in our consultative activity. The questionnaire was promoted to them and to others with a relevant registered interest on Talking Health and direct by Autism Oxford. In all there were 29 responses to the questionnaire and six people participated in the discussion forum.

The workshop has been reported in detail in a separate document and the main findings of this are included here. This is a full report on the other elements of the consultation.

9. The workshop

A workshop on the 10 December 2010 was attended by 68 people. Those who attended included people with AS and their carers, medical professionals including psychiatrists, representatives from Oxfordshire County Council, NHS Oxfordshire and the probation service and a wide range of voluntary sector organisations with an interest in AS.

9.1 Workshop outcomes

There were a number of topics which were significant elements of the workshop. The following were picked out as significant by the working groups

- Support
- Mainstream support
- Training
- Leadership
- Access
- GPs
- Awareness
- Tensions in priorities
In addition five more topics came up in several group discussions – these have been identified under the following heads from highest to lowest mentions:

- Diagnosis
- Links to children’s services
- Pathways
- Information
- Finance

9.2 Overarching themes
Diagnosis was discussed extensively across all the groups but the report notes do not reflect the extent and time spent on this. There seems to be a recognition that what is more important than diagnosis is making sure that services meet needs properly so diagnosis can be informal (i.e. not provided by a medical professional but by someone trained to identify AS) but followed up with personalised, individual support.

The very specific needs of those with AS were emphasised throughout. Services need to be personalised and flexible recognising that if diagnosis does not happen early it needs to be available at other points in the journey and that diagnosis should not happen in a vacuum – it must lead to active support of the person with AS through the system. There were also several suggestions that models already in place could be utilised to develop services for those with AS. For example piggy backing onto the learning disability friendship and support network system which is already there; using the early issues identification system in schools to extend to identifying those with AS.

10. The questionnaire
The full questionnaire is attached at Appendix 1.

10.1 Question 1:
“Please tell us a little more about yourself”

Four responses were made by those who consider themselves to have AS. Most responses came from people working with those with AS (11) and nine were carers or family members. This included some people who identified with more than one role. In addition six respondents did not meet any of these descriptions.

10.2 Question 2:
“The following options have been identified for people with AS and their family carers. Respondents were asked to rate the following on a scale of nought to five.

- Taking action to improve awareness and reduce misunderstandings - this might include working with staff and the general public.
- Increasing the knowledge of professionals using AS training
• Develop a clear pathway to diagnosis & assessment, especially in teenage years
• Increase access to, information, advice, advocacy
• Increase support particularly for employment, housing and daytime activities, including peer groups support
• Easing and improving the transition into adult services
• Improving support & respite for family carers.”

There was very little differentiation between the responses to this question. The development of a pathway was identified as most important and awareness was least important. However the weighting was 114 for the first 101 for the second so not a significant difference in responses.

There were some interesting additional comments to this question (16 additional comments made). Several mentioned diagnosis as being key to accessing services but by contrast it was also suggested that advice and support services were more important.

You cannot plan or deliver a service without diagnosis and assessment

Diagnosis and knowledge about how to work with AS is essential

I believe that advice and support services are more important than diagnosis as if there are no specific services for people with AS and their families, a diagnosis would not in itself lead to greater access to support

It is patently obvious that there is not yet a route for diagnosis across the county and access to support services is extremely limited for this group as they tend to fall outside access criteria.

Although awareness came out lower in the prioritisation it was mentioned quite strongly in the narrative responses. There were two strongly expressed views one of which cannot be quoted because it would serve to identify the respondent – the essence of these responses is that workplaces and education can often fail this group of people because of lack of awareness or support for those who do have awareness or are concerned about those with AS.

All our lives would have been much happier had there been more awareness and help.

There is also a need to make sure that all employers and professionals likely to come into contact with this group should have better training

Clear pathways were considered to be valuable

It needs information about how to get a diagnosis and assessment to be readily available and not simply subject to being in touch with the right person by chance.
It needs clear signposting for people with AS and their families and entry to that pathway should be made as easy as possible.

Practical help and the struggle to get help were also mentioned as important.

*Everything is constant fight for help.*

The question of transition was also mentioned in these responses.

I found that the support given to families in the transition from childhood to adolescence was that which was most appreciated by the families of the autistic person. They were also the least readily available.

**10.3 Question 3:**

“We want to make sure that this pathway works effectively. Here are some suggestions to make sure all the organisations involved work well together. Please tell us which you agree with, and also add your own ideas.

Please select as many of the options as you agree with in the list.

- If the individual agrees, organisations should share records of the people they work with, to avoid the need for individuals to repeat the same information over again
- When an individual is passed from one service to another, the first organisation should pass on detailed information to the second organisation. This is to be sure the second organisation will understand the needs of the individual so there is no need to start all over again.
- Organisations should alert other organisations working with the person with AS and their family carers if they have worries or concerns about the person they are dealing with.
- Organisations should know which other organisations are involved in working with the person with AS and their family carers.
- Individuals and families should know who else is working with the person with AS and their family carers.
- Communication between services should be as quick and effective as possible.
- Each individual should have a named key person, who will co-ordinate services provided and deal with all organisations involved.
- There should be systems that securely link up all the information about an individual and their needs. This will mean that information does not need to be repeated.
- People with AS and their family carers should not to have to meet lots of different people to get their needs met.
- One familiar building where people with AS and their family carers can meet professionals from different organisations for appointments.
Again there was not a significant difference between the weightings for this question. However rated most highly was ‘quick and effective communication between services’ least rated was ‘one familiar building where people with AS and their family carers can meet professionals from different organisations for appointments’.

There were some interesting comments from 16 respondents. There were no strong themes in the responses except to emphasise the importance of consent in sharing information which was mentioned by two people.

The role of family/carers was mentioned three times – they should be recognised as the expert, have the right to respite and have a choice about who to work with. Also it is important not just to have a key worker but to be able to choose not to work with that person if the relationship does not work.

There should be recognition that the carers or family may well be the 'expert' on an individual and along side that the recognition that a diagnosis does not mean that all those with Aspergers are the same or react the same to all situations.

The need to make the person the centre of decision was identified - not making decisions without involving them and designing the service around the individual.

It's starting with the person and then designing the service around needs and outcomes

Other views were; ensuring we are aware of all the people in Oxfordshire with AS; a psychologist to be identified by OBMH to focus on AS; development of a specific anxiety test recognising that manifestations of anxiety in AS are not predictable from the usual models.

...an AS sufferer does not manifest in the usual way and the lack of specialised tests may result in AS sufferers being undetected and forgotten.

10.4 Question 4:

“If you have any other comments or suggestions that you would like to add about the AS strategy and how the money is spent, please add them here:”

Fifteen people made additional comments. There was a theme that the expertise should be in the right place and existing expertise should be used. However within this there were a variety of ideas; that there should be access to a diagnostic service across county boundaries so that there could be a focused expertise; that AS/autism should not be considered as part of the mental health spectrum; that there are potential focal points for expertise such as Children in Touch; that teams could have a designated AS expert.

...actions that have a low priority in a 'professional's care plan' can be seen as highly important by others involved. The inclusion of the client and family and carers in the formulation of a care plan can help to overcome some of these difficulties.
AS clients desperately want to increase their social circles and need huge amounts of support and understanding in the right environment for this to be a realistic goal, slotting them in to other Mental Health settings isn't sustainable long term.

Concerns were raised about the small amount of money available for this work - this was mentioned by four of the respondents.

The amount of money available is limited at present and wouldn't be sufficient to have a specialist team housed in a drop-in centre for people with AS. However, one could start with having one/two specialist professionals who have worked with a number of people with AS and who are flexible and creative thinkers.

The money would go further if it would go directly to organisations that already work with AS, like children in touch.

Other points raised included the importance of employment support, that person centred services should be offered and agreed not services imposed by the provider and change must be carefully explained; social relationships were also raised as important.

It was also suggested there is another phase of transition which needs to be considered and planned for.

Many young adults are supported well by their parents and this masks the fact that as those parents get older three will be a need for much more support-and planning for what that will look like needs to begin at a much earlier stage when parents are able to help to prepare their children for future independence and work with professionals to enable transition to take place.

The importance of establishment of an autism board was mentioned as well. This is explored fully in the section reporting on the discussion forum.

In addition there were elements raised in the discussion forum which are further comments on the work rather than linked to the discussion – these are reported at this point. In particular there is a strong case of service investment which would/could ultimately save on expensive out of county placements. This would enable crises to be managed locally rather than unplanned diversion of resources to crises as they happen.

11. The discussion forum
A discussion forum was set up on Talking Health. This includes an option for members of the public to start their own related discussion strands, but this was not used by any respondents. The forum was initiated with a discussion topic of future governance for this work.

We asked
“We are thinking about the ways in which we can make sure the views of those affected by this consultation continue to be taken into account in future.

We think there are a number of options for doing this.

We could have an autism board. But what authority should it have? Who should it report to? Should the reporting be formal or informal?

We could have a stakeholder group to share views and ideas about the direction of our work.

Should we be looking at an all age structure or something that does not include children's services? What challenges would these approaches present us with?

What do you think?”

There was some support for a reference group and wide support for an autism board. However there was no agreement about how this would report. It might report to the Learning Disability Partnership board or to Oxfordshire County Council and NHS Oxfordshire/GP commissioners

It was suggested that there should be involvement from parents, those with autism and representation from national organisations (such as the National Autistic Society (NAS)) and local interest groups such as the carers forum. However there was a very detailed discussion of some of the issues involved in working with those with autism. We should be careful to avoid this being tokenistic, making sure that they are engaged properly, understand how to participate effectively and treated with respect and equal consideration by other members.

There was support for the board being across the spectrum because there are some overlaps in the services and needs. It was less clear whether there was support for an all age board – this might be too big and unwieldy and that risk should be taken into account. It was also suggested that there are significant differences in the needs of children and adults who have autism.

Other comments indicated that it is important that this method engagement is meaningful and that an autism board makes a difference and is not there simply to ‘tick a box’. It was important that it should influence spending, service provision, ensuring funding is not bundled up under other larger budgets and spent directly on the needs of this group ensuring that information about who is affected and services are available. We must ensure that the powers of the board are clearly defined.

12. **Glossary and references**

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

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

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

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

Thurrock model
http://www.thurrockparents.org.uk/

Liverpool model

13. Next steps
This report will be considered in the planning for the use of the small budget currently available. It will be taken into account in the decision about the future governance for work on autism. A future report will be made on how the comments made at this stage have impacted on delivery of services and all comments will be recorded on Talking Health. This report will be published on talking Health and an executive summary distributed to all those who have contributed.

14. Thanks
We would like to thank everyone who took time to contribute to the workshops, the questionnaire responses and the discussion forum. We have had much thoughtful wise and sensitive information to consider in development of the next stage of this work.
Appendix 1

Questionnaire

AS Syndrome

A questionnaire about the identified needs of people aged 14 and over in Oxfordshire

Over the past year some careful research has been done into the needs and aspirations of people with AS and their family carers. We are using the term AS to mean Asperger’s syndrome and other autistic spectrum conditions with no co-existing learning disability. We do not have the funds available to develop a new service, so intend to strengthen current services so that many of these needs can be met.

The report resulting from our research can be found here (insert link here)

We now want to know which needs are the most important. This will help us decide how best to spend the small amount of money available.

Please complete and return the following questionnaire by Friday 7 January 2011

1. Please tell us a little more about yourself

Please select up to 3 of the options in the list.

☐ I am a carer/family member of someone with AS syndrome
☐ I have been diagnosed or consider myself as someone who has AS syndrome
☐ My working role includes working with those with AS syndrome
☐ None of these apply
2. The following options have been identified for people with AS and their family carers. Please score each one on a scale of 0 to 5, where 0 means not important and 5 means very important:

Please give a score (from 0 to 5) to zero or more of the options in the list.

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<th></th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
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<tr>
<td>Taking action to improve awareness and reduce misunderstandings - this might include working with staff and the general public.</td>
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<tr>
<td>Increasing the knowledge of professionals using AS training</td>
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<td>Develop a clear pathway to diagnosis &amp; assessment, especially in teenage years</td>
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<td>Increase access to, information, advice, advocacy</td>
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<td>Increase support particularly for employment, housing and daytime activities, including peer groups support</td>
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<td>Easing and improving the transition into adult services</td>
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<td>Improving support &amp; respite for family carers.</td>
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If you have any particular reasons for the importance that you have given to these options, please let us know here:
The journey that people make through services is called a care pathway. Many agencies and organisations may be involved in this pathway. We call this multi-agency working. We need to make sure that all parts of the pathway work together so that care is delivered in a more effective way. An example of what a pathway looks like is shown here:

The words in the triangle say what the need is and the words outside the triangle say what will be done about those needs.

3. We want to make sure that this pathway works effectively. Here are some suggestions to make sure all the organisations involved work well together. Please tell us which you agree with, and also add your own ideas.

Please select as many of the options as you agree with in the list.

☐ If the individual agrees, organisations should share records of the people they work with, to avoid the need for individuals to repeat the same information over again.

☐ When an individual is passed from one service to another, the first organisation should pass on detailed information to the second organisation. This is to be sure the second organisation will understand the needs of the individual so there is no need to start all over again.

☐ Organisations should alert other organisations working with the person with AS and their family carers if they have worries or concerns about the person they are dealing with.

☐ Organisations should know which other organisations are involved in working with
the person with AS and their family carers.

- Individuals and families should know who else is working with the person with AS and their family carers.
- Communication between services should be as quick and effective as possible.
- Each individual should have a named key person, who will co-ordinate services provided and deal with all organisations involved.
- There should be systems that securely link up all the information about an individual and their needs. This will mean that information does not need to be repeated.
- People with AS and their family carers should not to have to meet lots of different people to get their needs met.
- One familiar building where people with AS and their family carers can meet professionals from different organisations for appointments.
- Other (please specify)

Please type your answer here if you selected 'Other (please specify)' above

4. If you have any other comments or suggestions that you would like to add about the AS strategy and how the money is spent, please add them here:
If you would like to hear the outcome of this work we would be happy to send you any details. Please complete your name and address below.

Name:
Address:

Email address:
Telephone number:

When you have completed this questionnaire you can post it as follows:
Communications & Engagement
FREEPOST RRRKBZBTASXU
NHS Oxfordshire
Jubilee House
5510 John Smith Drive
Oxford Business Park South, OXFORD OX4 2LH

ALL QUESTIONNAIRES SHOULD BE COMPLETED AND RETURNED BY 7 JANUARY

If you would prefer to complete it online or have any queries please see below:

How to answer the questions online
Take a look at the consultation pages on our website. You will be asked to register before you can get all the information.
https://consult.oxfordshirepct.nhs.uk/consult.ti/Urgentcarepilot/consultationHome

How to find out more

Write to the above address
Email: talking.health@oxfordshirepct.nhs.uk
Phone 01865 334641