

Getting in on the Act

Scrutinising services for adults with autism





The Centre for Public Scrutiny

The Centre for Public Scrutiny promotes the value of scrutiny in modern and effective government, not only to hold executives to account but also to create a constructive dialogue between the public and its elected representatives to improve the quality of public services.

The National Autistic Society

The National Autistic Society (NAS) is the UK's leading charity for people affected by autism. We were founded in 1962, by a group of parents who were passionate about ensuring a better future for their children.

Today we have over around 20,000 members, over 100 branches and provide a wide range of advice, information and support as well as specialist services to 100,000 people each year. A local charity with a national presence, we campaign and lobby for lasting positive change for people affected by autism. For more information, please visit www.autism.org.uk

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Foreword

For too long people with autism have been failed by a system that doesn't treat them as an individual and excludes them because they do not fit in with the way services are structured locally. The Autism Act 2009 aims to put an end to this, but change on the ground cannot solely be forced from the corridors of Whitehall. Local action is needed to deliver real and lasting change for people that have for too long and too often been failed.

The key question that we are getting people to ask up and down the country is, are you delivering care services tailored to meet the different needs of people who live in your area, or just providing a one size fits all solution?

The Government's vision for health and social care is one where frontline professionals are empowered to make the tough decisions about what and how services are delivered, where the people that use those services have a say in how they work and where there is clear accountability to make sure we protect taxpayers' money.

A key part of this scrutiny has to be done at the local level by elected councillors and this guide, and the others created by the Centre for Public Scrutiny, play a valuable role in ensuring that overview and scrutiny committees can do their job effectively.

Good scrutiny is not only about holding those responsible for local services to account, but about investigating how effective those services are in meeting people's needs and changing them accordingly. Listening and learning are not weaknesses they are strengths, and good thoughtful scrutiny helps us all improve.

Making sure that people with autism can lead fulfilling and rewarding lives is a goal that we all share. It requires an improved understanding of autism – in both public services and within wider society – and an increased ability to tailor services around the real needs of adults with autism at a local level by giving them choice and control through personalisation and by taking in to account the person and their individual circumstances. The National Autistic Society has been working to make sure this happens for a long time and we are starting to see great strides being taken.

It is vital that this momentum is maintained and overview and scrutiny committees will be very important in making sure this happens.



A handwritten signature in black ink, appearing to read 'Paul Burstow'.

Paul Burstow MP

Minister of State for Care Services

Introduction

All adults with autism¹ should be treated as equal citizens and appropriately supported to fulfil their potential. Unfortunately, we know that people with autism routinely struggle to access the services they need and consequently outcomes are poor. Research by the National Autistic Society (NAS) indicates:

- Over 60% of adults with autism rely on their families for financial support and 40% live at home with their parents
- 63% of adults with autism report that they do not have enough support to meet their needs
- 33% of adults with autism have experienced severe mental health problems because of a lack of support
- Just 15% of adults with autism are in full-time employment²

The Autism Act 2009, subsequent national strategy for improving support for adults with autism in England and its accompanying statutory guidance for local authorities and the NHS send a clear message to all statutory services about what has to be done to meet the needs of people with autism.

This guide helps Overview and Scrutiny Committees to monitor progress being made locally to improve outcomes for adults with autism by suggesting '10 questions' that local decision makers must answer to help ensure they are meeting their obligations under the Act.

What is autism?

Autism is a lifelong developmental disability that affects the way a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It is a spectrum condition, which means that, while all people with autism share three main areas of difficulty, their condition will affect them in different ways. The three main areas of difficulty are:

- Difficulty with social interaction. This includes recognising and understanding other people's feelings and managing their own. Not understanding how to interact with other people can make it hard to form friendships.
- Difficulty with social communication. This includes using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice.

1 The term autism is used throughout this document, as well as in the Adult Autism Strategy, statutory guidance and other related documents, to refer to all conditions on the autism spectrum including Asperger syndrome

2 All the above information is taken from the NAS I Exist report. For more information please visit <http://www.autism.org.uk/iexist>.

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- Difficulty with social imagination. This includes the ability to understand and predict other people's intentions and behaviour and to imagine situations outside of their own routine. This can be accompanied by a narrow repetitive range of activities.

Some people with autism are able to live relatively independent lives, others may need a lifetime of specialist support but most will require something in between.

Many people with autism may experience some form of sensory sensitivity or under-sensitivity, for example to sounds, touch, tastes, smells, light or colours. People with autism often prefer to have a fixed routine and can find change 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.

Estimates of the proportion of people with autism who also have a learning disability vary considerably, and it is not possible to give an accurate figure. Collecting together the existing research, the NAS believes that it is likely that over 50% of those with autism have an IQ in the average to high range and do not have a learning disability.

Asperger syndrome is a form of autism. People with Asperger syndrome typically have fewer problems with speaking than others on the autism spectrum, but they do still have significant difficulties with communication that can be masked by their ability to speak fluently. They are also often of average or above average intelligence.



Adult Autism strategy timeline



- **Autism Act**

Passed on 12th November 2009.

Puts a duty in legislation on the Government to produce a strategy and statutory guidance for health and social care to support the implementation of the strategy.

http://www.legislation.gov.uk/ukpga/2009/15/pdfs/ukpga_20090015_en.pdf

- **Fulfilling and rewarding lives: the strategy for adults with autism in England**

Published 3rd March 2010.

Policy document detailing central Government commitment, as well as actions for local authorities, the NHS and other statutory bodies

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113369

- **Towards 'Fulfilling and rewarding lives': The first year delivery plan for adults with autism in England**

Published April 2nd 2010

Document detailing the timescales and responsibilities for the first year.

Since the General Election, the Coalition Government has reviewed the plan and will decide which actions central Government will take forward. This does not affect the duties placed on local authorities and the NHS.

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_115115

- **Implementing Fulfilling and Rewarding Lives: Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy**

Published December 17th 2010.

To support the implementation of the strategy, this document sets out legal duties on local authorities and health bodies. Where the guidance says that something should be done, this means that they will have to do it unless they have a strong reason not to. Lack of resources will not necessarily be a good reason.

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_122847

- **Fulfilling and Rewarding Lives: Evaluating Progress**

Published 1st April, 2011

Guidance to help support Local Authorities and NHS organisations to monitor implementation of the strategy and statutory guidance

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_125703

- **Local self-assessment framework**

1st April, 2011

The self-assessment is primarily for commissioners to complete alongside local partners as a template to begin their planning to respond to the strategy and statutory guidance

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_128204.doc

- **Review of adult autism strategy**

2013

As part of the Adult Autism Act the Government must review the impact of the strategy with a view to ensuring that services are improving for people with autism.

Where are we now?

The Autism Act 2009 was England's first ever disability-specific law. This groundbreaking piece of legislation aims to revolutionise the way services are delivered to adults with autism.

The Act itself put two key duties on the Government. The first was to produce a strategy for adults with autism. This was published in March 2010. The second was that statutory guidance for local authorities and local health bodies had to be published by the end of 2010. On 17th December, 2010, this guidance was published.

According to the Autism Act, the purpose of the adult autism strategy is to improve the provision of services for adults with autism in England. This is extremely important part of the legislation as it underpins the reason the strategy exists and emphasises that action is needed in each area.

The adult autism strategy explains the different things that the Government will do to make sure adults with autism get the help that they need. The strategy also sets out actions for local councils and health services on improving local services.

The strategy focuses on five things:

1. Making sure that more people understand about autism.
2. Making it easier for adults to get a diagnosis of autism.
3. Ensuring adults with autism can choose how they live, and get the help that they need to do this.
4. Helping adults with autism to find jobs.
5. Helping local councils and health services to write plans so that the adults with autism who live in their area get the help that they need.

The Autism Act statutory guidance puts duties on local authorities, NHS bodies and NHS Foundation Trusts in order to meet the needs of people with autism living in their area.

Amongst other actions, the guidance clearly states that local authorities and the NHS should:

- Provide autism awareness training for all staff
- Must provide specialist autism training for key staff e.g. GPs and community care assessors
- Cannot refuse a community care assessment based solely on IQ
- Must appoint an autism lead in their area.
- Have to develop a clear pathway to diagnosis and assessment
- Need to commission services based on adequate population data.

In April 2011 the Government published a list of the 10 outcomes that should be achieved if the autism strategy and statutory guidance can be judged as a success. These are:

- Adults with autism achieve better health outcomes
- Adults with autism are included and economically active
- Adults with autism are living in accommodation that meets their needs
- Adults with autism are benefiting from the personalisation agenda in health and social care, and can access personal budgets
- Adults with autism are no longer managed inappropriately in the criminal justice system
- Adults with autism, their families and carers are satisfied with local services
- Adults with autism are involved in service planning
- Local authorities and partners know how many adults with autism live in the area
- A clear and trusted diagnostic pathway is available locally.

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- Health and social care staff make reasonable adjustments to services to meet the needs of adults with autism.

These ambitious objectives will be best achieved through partnership working between local authorities, the NHS, the voluntary sector and people directly affected by autism. Overview and Scrutiny Committees are ideally placed to support this process.

Why review implementation of the adult autism strategy?

Since the passing of the Autism Act, some authorities – particularly those who had a long standing history of engagement with the autism sector – have taken great strides to make sure services in their area work for people with autism. Other areas are finding it more difficult. More attention is needed to ensure that the right action is taken and outcomes are improved for adults with autism. This will not only improve the lives of people with autism but also cut waste and save money.

Research has shown that 1 in 100 children has autism and recent figures from the NHS Information Centre have confirmed a similar prevalence among adults.³ By applying the 1 in 100 figure we estimate that over 415,000 people in England have autism. Together with their families, they make up over one million people whose lives are touched by autism every single day. Yet, research has shown that all too often adults with autism are unable to access the support they need, which was why the Government took forward the Autism Act and the subsequent strategy and statutory guidance.

Over 60% of adults with Asperger syndrome or high functioning autism who responded to an NAS survey in 2007 said that they have experienced difficulties in accessing services and 52% of these were told that they do not fit easily into mental health or learning disability services.⁴ The issue of structural disadvantage does not only exist within local authorities – a clear support structure is absent among health services as well. When the NAS asked PCTs whether they have a process to support adults with autism who are not eligible for either learning disability or mental health services, 55% who responded said they do not.⁵ This explains in part why many people with autism are unable to access both the social services and health services that they need.

3 Brugha, T et al (2009) Autism Spectrum Disorders in adults living in households throughout England: Report from the Adult Psychiatric Morbidity Survey 2007 London: The NHS Information Centre for Health and Social Care.

4 Rosenblatt, M (2008) I Exist: The message from adults with autism in England. London: The National Autistic Society.

5 Ibid.

Further to this, for those that do access services, the lack of local data on adults with autism needed to help plan and commission services acts as a key barrier to getting the right support. This means people with autism are dealt with on a case-by-case basis and dealt with inconsistently. As a consequence people are too often inappropriately placed in out of area settings. On average, out of area placements will often be considerably more costly. Furthermore, the NAO found that although 50% of authorities commissioned some services out of area, over two-thirds were unable to provide figures for how much was spent.⁶ A lack of data can also mean that the scale of a particular local need can go unrecognised and therefore unmet.

This failure to deliver services that meet the needs of adults with autism not only has a devastating effect on the individual with autism it also has a serious cost implication. Nationally, the estimated cost of autism is £28 billion per annum (£25.5 billion for adults, and £2.7 billion for children).⁷ This averages out at £500 each year for every man, woman and child in the country.

It has been estimated that if we include the cumulative impact of service use, the need for accommodation assistance and low employment rates:

- Someone with high functioning autism or Asperger syndrome the lifetime cost is £3.1m⁸
- Someone with autism and a learning disability the cost was 50% higher at £4.6m⁹

This cost can be reduced by making sure services are accessible early. Indeed, when the National Audit Office (NAO) investigated public spending into adults with autism, they found that failing to invest in autism provision is a huge false economy.¹⁰ They also found that if local services identified, through autism specialist teams, and supported just 4% of adults with high functioning autism and Asperger syndrome the outlay would become cost neutral over time. Furthermore, they found that if they did the same for just 8% they could save the taxpayer £67 million per year.

The Liverpool Asperger Team, which is the longest-standing specialist Asperger service, reports identification rates of 14%. 4% therefore seems a very achievable figure for newly established autism teams, thus achieving a cost-neutral level of service is an entirely realistic prospect in the medium

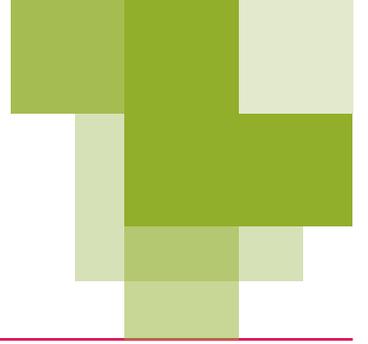
6 *ibid*

7 States no footnoted taken from: Knapp, M et al (2009) Economic cost of autism in the UK. Autism: Sage Publications and The National Autistic Society. Vol 13(3) 317-336.

8 If we apply the standard 3.5% discount rate - the amount recommended by the Treasury for public sector investment projects which has the effect of reducing the value of future costs and benefits in present day terms - this figure is £796,050

9 £1.23m (discounted)

10 Clark et al (2009) Supporting adults with autism through adulthood. The National Audit Office.



term. Although an initial cost with identification will be placed on the NHS – estimated to be around £28m for an eight per cent identification rate – the saving for local authorities would potentially be around £105m.¹¹

Too often people with autism are failed by services that should be helping them. But a lot of work has been done since the passing of the Autism Act 2009. It is for each area to work towards improving the outcomes of those with autism and for these areas to monitor progress. It is essential that we do not miss this opportunity to improve things for people with autism. Indeed, it makes it even more important that OSCs ensure that services in the area meet the needs of people with autism and ensure that they are cost-effective.



¹¹ ibid

10 Questions to ask

1. **Is there a plan in place to improve the outcomes of people with autism?**

Planning is essential to improving the outcomes for people with autism and the areas that have taken the biggest steps towards improving services have all started by producing a broad plan of action and appointing a senior individual to take it forward.

The Autism Act statutory guidance clearly states that local authorities should have a named joint commissioner/senior manager to lead commissioning of community care services for adults with autism in the area. This named commissioner should participate in relevant local and regional strategic planning groups and partnership boards, to ensure that the needs of adults with autism are being addressed.

Further to this, the statutory guidance also states that local authorities, NHS bodies and NHS Foundation Trusts should develop local commissioning plans for services for adults with autism across the spectrum, and review them annually.

- Has a senior commissioner been appointed to lead on implementing the adult autism strategy, and is this information public and accessible to all?
- Has a commissioning plan for services for adults with autism been developed?
- What are the key priorities of the commissioning plan and why?
- Has the Department of Health's self-assessment framework¹² been used to develop a plan for implementing the adult autism strategy and improving the outcomes of people with autism?
- What work is being undertaken at a regional level to implement the adult autism strategy?

2. **What relevant information is collected on adults with autism and how does it inform the commissioning of services?**

Exacerbating the problem of a lack of planning is a substantial lack of data both nationally and locally concerning adults with autism and their needs. It is the Government's vision that the Joint Strategic Needs Assessment (JSNA) acts as the primary source by which both health and social care services are to be commissioned. In 2009 just 20%

¹² http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_128204.doc



of JSNAs even mentioned autism, let alone ensured services were planned through this process.¹³

A lack of data collection on autism often means that many adults with autism only come into contact with services when their needs become acute, and they require more intensive, high level interventions and crisis management, such as psychiatric inpatient care. In NAS research, a third of adults with autism who responded to a survey said that they had developed serious mental health problems as a result of a lack of support. As the NAO report states: *“Beside the negative impact of such crises on a person’s life, acute services are also expensive, with inpatient mental health care costing between £200 and £300 per day.”*

In the statutory guidance it states that local areas should look to include autism in all key data collections. Such as the number of adults with autism who are:

- In employment in the area or likely to need employment support in order to work
- Placed in the area (and funded by) other local authorities or placed out of area
- In hospital or living in other NHS-funded accommodation
- Living at home on their own, or with family members, and not receiving health or social care services, or
- Living with older family carers

A number of authorities, who had started with no data on the numbers of adults with autism, have begun by carrying out a scoping exercise of their services, and using current information from education and children’s services and the wider community to come up with indicative prevalence information. They have then built on this, by changing the way they collect data in key areas.

- What data is collected on adults with autism and does this feed into the commissioning strategy?
- How many adults with autism are known to services and how does this compare with the prevalence estimates for autism?¹⁴
- Is data from children’s services, including transitions data, used to plan for future need of adult services?

¹³ *ibid*

¹⁴ The Department of Health’s PANSI website (<http://www.pansi.org.uk/>) has population estimates of adults with autism for each English local authority.

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- Is autism included in the Joint Strategic Needs Assessment?
 - How many individuals with autism are placed out of area and how much does this cost?
 - What steps are being taken to improve data collection of adults with autism?

3. **Do services locally meet the needs of all people with autism across the spectrum?**

Given the right support many more people with autism, and particularly those with high functioning autism or Asperger syndrome, will be much more able to live more independently in the community. Without this support there is a far greater risk of social exclusion. One of the best ways to make sure people don't fall into crisis is to ensure they can access appropriate services quickly. Often, if done early, these will be low cost information, advice and/or befriending services, which can prevent needs from escalating.

The goal of the adult autism strategy is to make sure that services are available for all adults with autism who need them. Historically, services for this group have been provided by specialised voluntary agencies that were in most cases started by parents of individuals with autism and mostly related to educational and residential services. Over time other providers from the private and voluntary sector have become involved but again these are primarily related to educational and residential services; only recently have more individualised approaches begun to materialise.¹⁵

One area that authorities may want to focus on concerns improving access to self directed support, such as direct payments. The Government's vision for adult social care is to make sure that the personalisation agenda should be open to all. Adults with autism, however, are often failing to access this type of support. This need not be the case and with the right support, such as appropriate advocacy and brokerage, people with autism should be able to take full advantage of all forms of self directed support where they want them and be given the freedom to access the services they choose.

¹⁵ Find out more Mills, R. & Francis, J. (2010) SCIE Research briefing 32: Access to social care and support for adults with autistic spectrum conditions (ASC). National Autistic Society, Research Autism and SCIE.

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- How easily can adults with autism in the area access support to the help they need to live more independently, including social skills training, independent living skills training and travel training?
 - Are there local voluntary services and groups working on supporting adults with autism in the area?
 - If adults with autism do not qualify for community care services, what other support are available locally e.g. support groups, information centres and/or befriending services?
 - Do all standard contracts for mental health and learning disability services require providers to demonstrate how reasonable adjustments for adults with autism are made, as the Adult Autism Strategy recommends?
 - How many individuals with autism receive some form of self directed support?
 - What support is available locally to help individuals with autism to benefit from the personalisation agenda, make informed choices, and manage their budgets, e.g. advocacy and/or brokerage services with expertise in autism?

4. Is there a trusted pathway to diagnosis in the area?

A key part of the adult autism strategy relies on improving diagnostic services for adults with autism. As such it is proposed that by 2013 there should be a clear pathway to diagnosis in every area. This service should be easily accessible and people made aware of it. In order to ensure this and accelerate the process, the statutory guidance recommends that local areas appoint a lead professional to develop diagnostic services for adults with autism.

Currently NICE are developing three clinical guidelines relating to autism which will give specific guidance on the appropriate care for people with autism. One of these guidelines – which was published in September 2011 – deals with recognition, referral and diagnosis of children with autism, while another – to be published in June 2012 – will offer similar advice for adults with autism, as well as covering ongoing management of the condition.

Nonetheless, in the Autism Act statutory guidance the Department of Health made it clear that action should be taken to ensure that a trusted pathway for diagnosis is available for adults with autism now. Also processes should be in place to ensure that a diagnosis leads to a community care assessment and a carer's assessment. Finally, commissioners should know what provision is available locally, how long people are waiting for a diagnosis and what their experience of the diagnosis process is.

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- Has the statutory guidance been followed and a lead professional been appointed to develop diagnostic and assessment services?
 - Is there a clear and trusted pathway in place for adults with suspected autism to access a multidisciplinary diagnostic assessment?¹⁶
 - How long have individuals with suspected autism been waiting to access a diagnostic and assessment service?
 - Does the area's diagnostic and assessment service have an information strategy to ensure individuals and families are given age appropriate support and guidance post-diagnosis?
 - Is a procedure in place, post-diagnosis, for an individual to be referred to a community care assessment?
 - Are carers of people with autism being identified and offered a carers assessment?
 - How do people in the area rate the diagnostic service?

5. **Are people with autism, families and carers involved with service planning and delivery?**

The autism strategy sets out the principle that adults with autism (and their families and carers) should be involved in decisions not only about their own care, but also about service design and planning in their local area. The primary route to involve the wider community is through Autism Partnership Boards.

These boards should be multi-agency forums that bring together key commissioners and the autism community to identify local priorities and enable a more strategic approach to developing better outcomes for people with autism. There are a large number of these boards set up across England already. For example, nearly all of the local authorities in the south west region have established such boards, the members of the Greater Manchester Autism Consortium have had autism partnership boards for over 10 years (called autism services development groups or ASDGs) and a vast number have been established across the rest of England.

Clearly, not everyone will be able to attend an autism partnership board and some authorities have found it useful to establish wider forums for people with autism and separate parent/carers forums. From these forums, representatives can attend partnership boards. This

¹⁶ More information about diagnostic pathways, with examples of the pathway used in Bristol and Liverpool, can be found on the NAS website <http://www.autism.org.uk/working-with/autism-strategy/diagnosis/diagnostic-pathways.aspx>



helps to both empower individuals and ensure that a wide selection of views is heard.

- How are adults with autism and their families/carers involved in the planning and delivery of services? Has an Autism Partnership Board/Development Group been established?
- Is there a system for people with autism and their families to give feedback about their experiences of services? If so, are people aware of this?
- How do other relevant planning and strategy groups, either autism specific or pan-disability (such as the learning disability partnership boards/carers forum), influence the planning and delivery of services?
- Is there a mechanism for local organisations and frontline professionals to be involved in the planning and delivery of services?
- What work is being done to improve participation and empower all individuals to be involved in the planning and delivery of services, including those who may be harder to reach?

6. Do children with autism make successful transitions to adult services and support?

Transition to adulthood can be particularly difficult for young people with autism. As a result of their disability, many find change difficult to cope with and there is frequently a lack of understanding of their autism and a dearth of provision to meet their needs.

Frequently, transition planning only begins when individuals are approaching the end of their schooling or, worse still, after they have left school and not at 14 when statutory guidance sets out that planning for all children with a statement should begin. In too many cases where transition planning is taking place, it is happening without the involvement of adult social services.

Poor transition creates a chasm between the aspirations of young people with autism and the reality experienced by many adults on the autism spectrum, with serious repercussions for the individual, their families and for public expenditure. This is why the adult autism strategy and statutory guidance place so much emphasis on improving transition.

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- At what age does planning for transition begin for young people with autism in the area?
 - What proportion of children with autism and a) a statement; b) on school action plus; or c) on school action have a transition plan?
 - How are children and parents involved in developing transition plans?
 - How are health, adult social services and other agencies – such as housing – involved in transition planning?
 - Are procedures in place to monitor transition from child services to adult services?
 - Are protocols in place to ensure a smooth transition between child and adolescent mental health services (CAMHS) and adult mental health services, in line with the statutory guidance?
 - For those not eligible for adult services, how are individuals signposted to other sources of support available locally and nationally?

7. Are professionals aware of the needs of adults with autism?

Limited awareness of autism by mainstream services - such as employment, benefit and housing advice services - often leads to an escalation of needs. The adult autism strategy makes it clear that the most important step towards improving services in an area is to increase awareness and understanding of autism. To aid this, the Department of Health invested £500,000 in the development of training materials.¹⁷

The statutory guidance explicitly says that local authorities, NHS bodies and NHS Foundation Trusts should seek ways to make autism awareness training available to all staff working in health and social care. Also there must be a route whereby staff can develop specialist knowledge of autism, particularly for GPs and those responsible for conducting community care assessments.

When planning or commissioning training, organisations should, where possible, involve adults with autism, their families and carers, and autism representative groups. This may be in terms of inviting them to comment on or contribute to training materials, or asking them to talk to staff about autism and how it affects them, or to provide the training.

¹⁷ More information can be found the further information section at the end of this document

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- Is there a strategy in place detailing how autism training will be rolled out across all mainstream services?
 - Are adults with autism, their families and carers involved in training staff?
 - Has there been a staff survey to understand general awareness of autism and which areas are most in need of development?
 - Do all public services include autism awareness training as part of their standard equality and diversity training programmes?
 - Do staff working directly with people with autism have appropriate autism training and how are their ongoing training needs met?
 - How confident are professionals in the area at recognising autism and making reasonable adjustments?
 - How many professionals have specialist knowledge of autism in the area, particularly GPs and community care assessors, and what steps are being taken make sure professionals have a route through which they can become experts?
 - How are training courses evaluated and what impact has autism training had?

8. **Are adults with autism economically active?**

Not enough adults with autism are in full-time employment. Although not everyone with autism can work, many have a lot to offer employers. Nevertheless, NAS research indicates that just 15% are in full-time paid employment; and only 9% are in part-time employment.

Long-term unemployment and the subsequent isolation can lead to mental and physical health problems. Furthermore, the health, social and economic benefits of work accrue not just to the individual but to the wider family and to society more broadly. The most authoritative estimate puts the costs of lost employment for people with autism in the UK at £9 billion a year.¹⁸

People with autism often have a great many strengths. They can be very committed, loyal and reliable, but employers often lack awareness of this. Furthermore, people with autism generally have very limited social networks, which exacerbates the difficulties they have finding employment. Indeed the evidence suggests that where people do find employment, it is often through family networks.¹⁹

¹⁸ 36% of £25 billion: Knapp, M et al (2007) The economic consequences of autism in the UK

¹⁹ Forsythe et al (2008) Benefits and employment support schemes to meet the needs of people with an Autistic Spectrum Disorder: Report for the National Audit Office

A key goal of the adult autism strategy is to increase the number of adults with autism, who can work, in employment. For this to happen, local services need to be properly coordinated: without better education, training and support people with autism will continue to be excluded from the labour market.

- How many people with autism known to services are in paid employment?
- Which employment support services operate in the area and are they equipped to support people with autism?
- How many people with autism access employment support services and how long have they been trying to find employment for the people they support?
- Are there volunteering or apprenticeship schemes in the area that support people with autism to develop essential skills?
- Are employment and training – such as social skills training - specifically considered as part of transition plans and what support is given to people with autism in further education?
- How do community care services encourage and support individuals to find work?
- Has work been done to raise awareness of autism amongst the local business community such as the local chamber of commerce?

9. **Is work towards implementing the adult autism strategy being monitored, evaluated and adapted?**

There is a lot of good, yet patchy, work that currently goes on to support adults with autism across health and social care. The Department of Health's adult autism strategy and statutory guidance seek to ensure that this best practice is spread across the country and all adults with autism lead fulfilling and rewarding lives.

To do this, it is vital that plans are drawn up, implemented and then evaluated. It is also essential that when making decisions about the restructuring of services - particularly in education, health and social care – that the needs of adults with autism are considered. As mentioned earlier, the whole point of the Autism Act 2009 is to improve services for adults with autism. Overview and scrutiny is essential in ensuring local areas are progressing towards this goal.

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- What steps are being taken to monitor and evaluate the implementation of the adult autism strategy locally?
 - Are the views of adults with autism and families being used to evaluate progress?
 - Has progress been evaluated using the local self assessment framework²⁰ and is this assessment available to the public?
 - How are the needs of adults with autism and their families/carers given consideration when reforms occur to public services which affect their daily lives?
 - What action is being taken to ensure that reforms due to take place in health, social care and education will meet the needs of adults with autism locally?
 - What would be the benchmark for success in the area?

10. **What recommendations can be made in respect of the areas identified above?**

Recommendations should always be SMART. This will increase the chances that they will be implemented. SMART stands for:

- Stretching—be ambitious and challenging
 - Measureable—be specific and quantify the recommendations where appropriate
 - Agreed—try to get ‘buy-in’ in advance and some ownership from those who will have to implement them
 - Realistic—while being ambitious, there is no point in making generic recommendations that no one can implement
 - Time-bound—set a date for implementation and review their success at this point
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²⁰ Self assessment framework can be found: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_128204.doc

Further information

NAS Adult Autism strategy website

<http://www.autism.org.uk/autismstrategy>

Easy Read and alternative colour contrast versions of strategy (and other resources)

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113369

National Audit Office (NAO) report

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

NAS Good Practice Guide

<http://www.autism.org.uk/en-gb/working-with/health.aspx>

NHS Confederation briefing

http://www.nhsconfed.org/Publications/Documents/Briefing_202_MHN_autism.pdf

SCIE Research briefing 32: Access to social care and support for adults with autistic spectrum conditions (ASC)

<http://www.scie.org.uk/publications/briefings/briefing32/index.asp>

SCIE at a glance 21: Implications for people with autistic spectrum conditions and their family carers

<http://www.scie.org.uk/publications/ataglance/ataglance21.asp>

NAS Involving people with autism: a guide for public authorities

<http://www.autism.org.uk/Working-with/Social-care-and-support/DED-guidance-for-public-authorities.aspx>

Department of Health. Services for adults with autistic spectrum conditions (ASC): Good practice advice for primary care trust and local authority commissioners

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

NAS. Good practice in supporting adults with autism: guidance for commissioners and statutory services

http://www.google.co.uk/url?q=http://www.autism.org.uk/~media/NAS/Documents/Working-with/Social-care/Good_practice_in_support_adults_with_autism.ashx&sa=U&ei=tRygTta4MYm_8gOQ7tnFBQ&ved=0CBoQFjAA&usg=AFQjCNHiX2ICN0xnxuuZ00Phq5QmmxpoMQ

Further information – training



In order to improve autism awareness and the development of more specialist training, the Department of Health has invested £500,000 in the development of training for health and social care staff; commissioning the following projects:

Royal College of Psychiatrists (RCPsych)

The RCPsych project produces training videos of diagnostic interviews for psychiatrists and other healthcare professionals. The videos highlight common impairments found in adults with Asperger syndrome. Access to the resource is restricted to psychiatrists and other healthcare specialists for training purposes only. [Find out more.](#)

The National Autistic Society

The NAS project identifies the key issues affecting service providers and commissioners in implementing the autism strategy, and develops an online resource to support them in doing so. [Find out more.](#)

The Social Care Institute for Excellence (SCIE)

The SCIE project aims to improve understanding of autism among social care professionals, producing videos about the experiences of people with autism and the support the need. [Watch the videos here.](#)

<http://www.scie.org.uk/socialcaretv/topic.asp?guid=36fd44de-5a56-4a18-9224-18f23b72c7c5>

British Psychological Society (BPS)

The BPS project will develop e-learning modules on autism from introductory to specialised levels, and will create a central online network connecting knowledge and resources, concluding in summer 2011. To find out more contact: The BPS Learning Centre, Tel: 0116 252 9925, Email: learningcentre@bps.org.uk or visit www.bps.org.uk/news/raising-awareness-adult-autism

Oxford University

This project builds upon Oxford University's previous research which explored the experiences of people with autism (read findings here) and parents (read findings here). It looks specifically at the experience of siblings (aged 16+) and grandparents. [Find out more.](#)

Skills for Health/Skills for Care

The Department of Health commissioned the NAS to create a framework for training health and care staff in autism. The framework includes guidance on training content, methods of delivery and defining priority learning needs for the wide variety of different job roles across health and social care organisations. [Find out more](#) or contact Steven Owens, Tel: 0141 221 8090, Email: training@nas.org.uk

Royal College of Nursing (RCN)

The Department of Health have funded two RCN projects. The first is a poster on ten points to consider when dealing with people with autism. [Download](#) the second a nurses' guide on the autism strategy and its implementation. It will be published in two of their journals; Learning Disability Practice and Mental Health Practice, in 2011.

Royal College of General Practitioners (RCGP)

The RCGP has developed an e-learning course for GPs and other primary care professionals, aimed at improving professional standards in the care of people with autism. It consists of four sessions focussing on improving understanding of autism, diagnosis and post-diagnostic support, and the management of transition; improving data collection and services commissioning; and making primary healthcare settings more accessible. The RCGP worked to produce a patient experience-centred e-learning package. Access to the training resource is restricted to individuals registered with the RCGP. [Find out more.](#)



