

Title: Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy Lead department or agency: Health Other departments or agencies:	Impact Assessment (IA)
	IA No: 7003
	Date: 01/12/2010
	Stage: Final
	Source of intervention: Domestic
	Type of measure: Primary legislation

Summary: Intervention and Options

What is the problem under consideration? Why is government intervention necessary?

Adults with autism and their family carers face many barriers in their every day lives and in accessing the services and support they need to have their condition identified and to live independently within the community. This is in part because of: health and social care professionals not having sufficient knowledge and skills to detect, interact with and understand their needs; insufficient information on support available for people with autism and their families; and a lack of focus on, or priority given to, commissioning health and social care services despite earlier good practice guidance. Intervention, in terms of statutory guidance, will bring new priority and focus for health and social care commissioners in planning and commissioning services to meet these needs and improve health and care outcomes for adults with autism and their families.

What are the policy objectives and the intended effects?

The policy objectives are to support independent living and improve outcomes for people with autism and their families by improving information, increasing identification of autistic spectrum conditions and assessment of need, where appropriate enhancing access to social care services, and improving access to healthcare and health interventions. The intended effects are better quality of life and inclusion for this disadvantaged group

What policy options have been considered? Please justify preferred option (further details in Evidence Base)

Two options have been considered:

Option 1 – do nothing

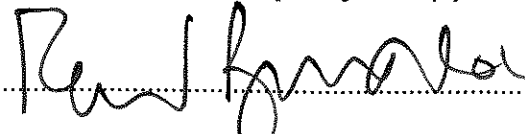
Option 2 – set out a clear framework for health and social care bodies to: develop local models to improve staff understanding and knowledge of autism and the needs of people with autism and their families with the aim of improving identification and diagnosis of autism; provide appropriate training to assess need; and to give greater priority to commissioning and planning health and care services to meet identified need

Option 2 is the preferred option as without such a framework, and duty under S7 of the LASS Act 1970, health and social care bodies are likely to continue to give insufficient priority to meeting the needs of this disadvantaged group

Will the policy be reviewed? It will be reviewed What is the basis for this review? duty to review	If applicable, set review date 02/2013 If applicable, set sunset clause date NA
Are there arrangements in place that will allow a systematic collection of monitoring information for future policy review?	No

Ministerial Sign-off For final proposal stage Impact Assessments:

I have read the Impact Assessment and I am satisfied that (a) it represents a fair and reasonable view of the expected costs, benefits and impact of the policy, and (b) the benefits justify the costs.

Signed by the responsible Minister:  Date: 2 Dec 2010

Summary: Analysis and Evidence

Policy Option 2

Description: Set out a clear framework for health and social care bodies to: improve staff understanding and knowledge of autism and the needs of people with autism and their families; provide appropriate training to assess need; and to give greater priority to commissioning and planning health and care services to meet identified need

Price Base	PV Base	Time Period	Net Benefit (Present Value (PV)) (£m)		
Year 2011	Year 2011	Years 40	Low: Optional	High: Optional	Best Estimate: -909.4

COSTS (£m)	Total Transition (Constant Price) Years	Average Annual (excl. Transition) (Constant Price)	Total Cost (Present Value)
Low	Optional	Optional	Optional
High	Optional	Optional	Optional
Best Estimate	0.04	23	909.4

Description and scale of key monetised costs by ‘main affected groups’

The key components of the cost of the guidance will be: Online Toolkit, Training of key professionals and staff, Joint Commissioners, Lead Professionals, Diagnosis and Assessment, and Development of Services. Opportunity costs represent 20% of total Net Present Value costs.

Other key non-monetised costs by ‘main affected groups’

NA

BENEFITS (£m)	Total Transition (Constant Price) Years	Average Annual (excl. Transition) (Constant Price)	Total Benefit (Present Value)
Low	Optional	Optional	Optional
High	Optional	Optional	Optional
Best Estimate	NA	NA	NA

Description and scale of key monetised benefits by ‘main affected groups’

Currently no available information to monetise the benefits associated with the statutory guidance.

Other key non-monetised benefits by ‘main affected groups’

Non-quantified benefits include improvement in the access and quality of services for people with autism and their carers, greater information and awareness of the needs of people with autism, improved outcomes and life expectancy for people with autism, increased effectiveness of service delivery based on better local information and assessment of needs, individuals better supported to contribute materially to society through work.

Key assumptions/sensitivities/risks

Discount rate (%) 3.5%

Many of the costs depend on a variety of assumptions, outlined in the evidence section of the impact assessment. Toolkit, training, lead professionals and lead commissioners have only small risks associated with cost escalation. The scale of costs relating to increased assessment and increased use of public services is subject to uncertainties regarding those coming forward for assessment. The risks to costs per adult with autism are low but a higher risk should be attached to the numbers coming forward.

Direct impact on business (Equivalent Annual) £m):			In scope of OIOO?	Measure classified as
Costs: NA	Benefits: NA	Net: NA	No	NA

Enforcement, Implementation and Wider Impacts

What is the geographic coverage of the policy/option?	England				
From what date will the policy be implemented?	01/04/2011				
Which organisation(s) will enforce the policy?	DH, CLG, PCTs, SHAs, LAs.				
What is the annual change in enforcement cost (£m)?	NA				
Does enforcement comply with Hampton principles?	Yes				
Does implementation go beyond minimum EU requirements?	No				
What is the CO ₂ equivalent change in greenhouse gas emissions? (Million tonnes CO ₂ equivalent)	Traded: NA		Non-traded: NA		
Does the proposal have an impact on competition?	No				
What proportion (%) of Total PV costs/benefits is directly attributable to primary legislation, if applicable?	Costs: All		Benefits: All		
Annual cost (£m) per organisation (excl. Transition) (Constant Price)	Micro	< 20	Small	Medium	Large
Are any of these organisations exempt?	No	No	No	No	No

Specific Impact Tests: Checklist

Set out in the table below where information on any SITs undertaken as part of the analysis of the policy options can be found in the evidence base. For guidance on how to complete each test, double-click on the link for the guidance provided by the relevant department.

Please note this checklist is not intended to list each and every statutory consideration that departments should take into account when deciding which policy option to follow. It is the responsibility of departments to make sure that their duties are complied with.

Does your policy option/proposal have an impact on...?	Impact	Page ref within IA
Statutory equality duties ¹ Statutory Equality Duties Impact Test guidance	Yes	16
Economic impacts		
Competition Competition Assessment Impact Test guidance	No	
Small firms Small Firms Impact Test guidance	No	
Environmental impacts		
Greenhouse gas assessment Greenhouse Gas Assessment Impact Test guidance	No	
Wider environmental issues Wider Environmental Issues Impact Test guidance	No	
Social impacts		
Health and well-being Health and Well-being Impact Test guidance	No	16
Human rights Human Rights Impact Test guidance	Yes	16
Justice system Justice Impact Test guidance	No	
Rural proofing Rural Proofing Impact Test guidance	No	
Sustainable development Sustainable Development Impact Test guidance	No	

¹ Race, disability and gender Impact assessments are statutory requirements for relevant policies. Equality statutory requirements will be expanded 2011, once the Equality Bill comes into force. Statutory equality duties part of the Equality Bill apply to GB only. The Toolkit provides advice on statutory equality duties for public authorities with a remit in Northern Ireland.

Evidence Base (for summary sheets) – Notes

Use this space to set out the relevant references, evidence, analysis and detailed narrative from which you have generated your policy options or proposal. Please fill in **References** section.

References

Include the links to relevant legislation and publications, such as public impact assessment of earlier stages (e.g. Consultation, Final, Enactment).

No.	Legislation or publication
1	Autism Act 2009 www.opsi.gov.uk/acts/acts2009/pdf/ukpga_20090015_en.pdf
2	Consultation on Autism Strategy (2009) http://www.dh.gov.uk/en/Consultations/Liveconsultations/DH_098587
3	Autism Strategy (2010) http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113369
4	Consultation on Statutory Guidance for local authorities and NHS organisations to support implementation of the autism strategy (2010) http://www.dh.gov.uk/en/Consultations/Liveconsultations/DH_118058

Evidence Base

Ensure that the information in this section provides clear evidence of the information provided in the summary pages of this form (recommended maximum of 30 pages). Complete the **Annual profile of monetised costs and benefits** (transition and recurring) below over the life of the preferred policy (use the spreadsheet attached if the period is longer than 10 years).

The spreadsheet also contains an emission changes table that you will need to fill in if your measure has an impact on greenhouse gas emissions.

Annual profile of monetised costs and benefits* - (£m) constant prices

	Y ₀	Y ₁	Y ₂	Y ₃	Y ₄	Y ₅	Y ₆	Y ₇	Y ₈	Y ₉	Y10-Y19	Y20-Y29	Y30-Y39
Transition costs	0	-	-	-	-	-	-	-	-	-			
Annual recurring cost	19	17	18	19	18	19	20	21	21	22	239	246	229
Total annual costs	19	17	18	19	18	19	20	21	21	22	239	246	229
Transition benefits	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Annual recurring benefits	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Total annual benefits	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A



Microsoft Office
Excel Worksheet

* For non-monetised benefits please see summary pages and main evidence base section

Use the following headings and add or delete as appropriate:

One In One Out

Not applicable.

Sunset Clause

The Secretary of State has a duty under the Autism Act 2009 to keep the Strategy and guidance under review and publish revised Strategy and guidance if deemed necessary.

Impact of all actions to come out of the Strategy and guidance will be assessed– as well as the other steps already taken to transform services for adults with autism in England and Wales – as part of the formal review, in 2013. Arrangements for the review of the Strategy and statutory guidance are currently being developed and will be communicated following publication of the statutory guidance.

1. INTRODUCTION AND BACKGROUND

People with autism do not have equality of access to, and quality of response from, local services and healthcare, nor do they have sufficient choice over where and how they live their lives.

There is a developing body of evidence – including that laid out by the National Audit Office in their 2009 report *Supporting people with autism through adulthood*– that adults with autism, and their families, face many barriers in their everyday lives and in accessing the services and support that they need, including:

- their condition being overlooked or misunderstood by professionals and by society,
- experiencing difficulties in the services and support they need to live independently within the community
- difficulty in gaining long-term, meaningful employment.

We have estimated that around 100,000 adults with autism do not currently receive services.

In response to this developing body of evidence the previous Government set out a vision to reduce exclusion and ensure adults with autism are able to participate fully in society in the *Fulfilling and rewarding lives: the strategy for adults with autism in England, 2010*.

The Autism Act 2009, the first ever piece of disability-specific legislation in England, requires the development by 1 April 2010 of “a strategy for meeting the needs of adults in England with autistic spectrum conditions by improving the provision of relevant services to such adults by local authorities, NHS bodies and NHS foundation trusts.”

Guidance for local authorities and NHS organisations to support implementation of the autism strategy will be issued under section 2 of the Autism Act 2009. As set out in section 3 of the Autism Act 2009, it is to be treated as though it were guidance issued under section 7 of the Local Authority Social Service Act 1970 (LASS Act). This means that local authorities must “follow the path charted by the guidance, with liberty to deviate from it where the authority judges on admissible grounds that there is good reason to do so, but without freedom to take a substantially different course.” The Autism Act lays out that for the purposes of the autism strategy, section 7 of the LASS Act also applies to NHS bodies as defined.

2. RATIONALE FOR GOVERNMENT INTERVENTION

Over recent years, it has become increasingly clear that a significant proportion of adults with autism across the whole autistic spectrum, are excluded both socially and economically. The National Audit Office report reveals widespread evidence of services not meeting need across the public sector and made recommendations to central and local government to deliver change.

Understanding of autism on the part of health and social care professionals and staff, and the difficulties service-users and their family carers experience in interacting with the health and social care system are two areas where focus is needed. Although good practice guidance has previously been issued by DH on improving access to services for people with autism, that guidance has not been picked up across the piece by health and social care bodies, and it is clear that – in the current economic climate – little action will be taken to improve outcomes for this disadvantaged group without further government intervention via the autism strategy and statutory guidance to set out clearly the importance of such action

The Autism Act 2009 requires the Government to consult on and publish statutory guidance for health and social care to support the strategy's delivery no later than 31 December 2010 and in this context, final guidance is now being published following the conclusion of the Spending Review, and the end of the specified consultation period on the draft guidance.

The Autism Act required that guidance covers the following:

- the provision of relevant services for the purpose of diagnosing autistic spectrum conditions in adults;
- the identification of adults with such conditions;
- the assessment of the needs of adults with such conditions for relevant services;
- planning in relation to the provision of relevant services to persons with autistic spectrum conditions as they move from being children to adults;
- other planning in relation to the provision of relevant services to adults with autistic spectrum conditions;
- the training of staff who provide relevant services to adults with such conditions;
- local arrangements for leadership in relation to the provision of relevant services to adults with such conditions.

However, there is no requirement under the Act that these seven areas are covered separately.

Therefore, in recognition of the fact that there are important links between some of these areas, this guidance is structured as follows:

- A. Training of staff who provide services to adults with autism
- B. Identification and diagnosis of autism in adults, leading to assessment of needs for relevant services
- C. Planning in relation to the provision of services to people with autism as they move from being children to adults
- D. Local planning and leadership in relation to the provision of services for adults with autism.

This structure helps clarify the links between these areas and simplifies the guidance. It also ensures the guidance is more clearly focused on the outcomes we seek.

3. OUTCOMES SOUGHT

The autism strategy, Fulfilling and Rewarding Lives, set out a clear vision for transforming the lives of adults with autism:

'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.'

As the strategy acknowledged, this vision is a long-term goal. However, the policies and practices outlined in the guidance provide the next important step towards that goal. In particular, the guidance seeks to:

- improve the way local health and social care services identify the needs of adults with autism, and
- ensure locally identified needs are met more effectively.

By achieving these outcomes, we will deliver tangible improvements in services and support for people with autism. This in turn will drive progress towards the long-term goal of improving the lives of adults with autism, their families and carers – which will also ultimately benefit the wider community.

4. OPTIONS

There are two options:

Option 1 – Do nothing.

Option 2 – set out a clear framework for health and social care bodies to: develop local models to improve staff understanding and knowledge of autism and the needs of people with autism and their families with the aim of improving identification and diagnosis of autism; provide appropriate training to assess need; and to give greater priority to commissioning and planning health and care services to meet identified need

1. Do nothing

This is not an option we can pursue as in not consulting on and producing guidance, the Government will be in contravention of the Autism Act 2009.

2. Set out a clear framework for health and social care bodies to: develop local models to improve staff understanding and knowledge of autism and the needs of people with autism and their families with the aim of improving identification and diagnosis of autism; provide appropriate training to assess need; and to give greater priority to commissioning and planning health and care services to meet identified need

Option 2 is the preferred option as without such a framework, and duty under S7 of the LASS Act 1970, health and social care bodies are likely to continue to give insufficient priority to meeting the needs of this disadvantaged group

There is also a legislative imperative imposed by the Autism Act 2009 to consult on and issue guidance for health and social care bodies to support implementation of the autism strategy no later than end December 2010. To do nothing, is therefore invalid as the Secretary of State would be in breach of the Act.

Although there are a number of options for developing the guidance for local authorities and NHS organisations to support implementing the autism strategy, the guidance that has been produced is the only option which is achievable within the current financial constraints.

5. COSTS AND BENEFITS

Equality of access is a fundamental principle of UK public services. But it is clear that, too often, adults with autism are not able to access the services they are entitled to or the support they need. Sometimes this is through lack of information; other times it is because services are designed and delivered in ways that – unwittingly – exclude adults with autism.

This Strategy and guidance set out to change this and ensure that more adults with autism are able to benefit fully from public services by:

- requiring services to make reasonable adjustments for adults with autism
- removing artificial barriers to and between services
- ensuring transition planning gives young people with autism the right start in their adult life, and
- improving access to information, advice and guidance, particularly around benefits, entitlements and employment support.

6. BENEFITS

Below is a broad level summary of the areas which benefits could be realised with the successful implementation of the Strategy and guidance.

Increased awareness and understanding of autism amongst front-line professionals

Increasing awareness and understanding may lead to:

- People with autism being more able to use services to improve their health and care outcomes.
- Less stereotyping of people with autism and better provision of services to meet the actual needs of individuals.
- Adjustments being made by professionals interacting with people with autism in their approach to communication with or expectations of people with autism.
- Better ability for professionals to understand and respond appropriately to people with autism.
- NHS practitioners being able to identify potential signs of autism, so they can refer for clinical diagnosis if necessary, but more importantly so they can understand how to adapt their behaviour and particularly their communication when a patient either has been diagnosed with autism or displays these signs.
- Adults with autism feeling more comfortable seeking healthcare services – reducing the likelihood of challenging behaviour in healthcare settings, and enabling their health needs to be identified and addressed earlier.

Developing a clear, consistent pathway for diagnosis of autism in every area, which is followed by the offer of a personalised needs assessment.

Drawing on evidence of the outcomes of pathways developed for other conditions it is likely that a consistent pathway to diagnosis could lead to:

- Diagnosis being more accessible enabling better and more consistent access to appropriate interventions,
- Better access to diagnosis and appropriate referral should have the effect of preventing deterioration leading to avoidable and inappropriate crisis admissions to services
- The expansion of adults with autism's health records in the future, which can be referred to when necessary to inform care decisions or support applications for additional services.
- An agreed standard for what information should be recorded and how it should be shared with other services which will improve the ability of health and social care professionals to make decisions about the care and support needs of people with autism.

Improving access for adults with autism to the services and support they need to live independently within the community

Improving access may lead to:

- Less chance of delay in diagnosis and treatment of often minor health conditions which could potentially become more damaging to overall health
- Identification of care and support needs for individuals and their family carers
- Adults with autism being better able to access appropriate benefits and employment advice – making it easier to get into work.
- Enabling adults with autism to access and stay in education.

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

Enabling local partners to develop relevant services may lead to:

- The provision of specific services helping adults with autism to live more independent and fulfilling lives within society.
- Better planning for adults with autism that will produce the key priorities, but also help map existing services, identifying in particular voluntary sector services that would benefit from additional support and ways to build their capacity.

- The clarifying of local responsibility and shared regional direction which will help strengthen the development of services for adults with autism, and improve their access to mainstream services.

7. COSTS

One of the underlying principles of the statutory guidance is to avoid new burdens or extra requirements that health and social care professionals must meet. Instead, the emphasis is on making sure existing policies are followed: that is why throughout the guidance, there is a clear reminder of what existing policies, responsibilities and duties are.

Summary of costs:

The requirements we have examined as part of the impact assessment are:

- Online toolkit
- Training for healthcare professionals and health and social care staff
- Joint commissioners to commission autism services
- Lead professionals to develop diagnostic and assessment services
- Diagnosis and Assessment
- Development of Services

Due to lack of availability of data, assumptions have been made regarding the costs, which are detailed below.

Table 1: Costs of Autism Strategy, including opportunity costs (£m) (2011/12 prices)²

		Y0	Y1	Y2	Y3	Y4	Y5	Y6	Y7	Y8	Y9	Y10- Y19	Y20- 29	Y30- Y39
Toolkit	DH	0.006												
Training (e-module)	DH	0.030												
Training (workshop)	NHS	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.1	0.0	0.0
Training (workshop)	LA	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Opportunity Cost of e-learning	NHS	1.7	1.7	1.6	1.5	0.6	0.6	0.5	0.5	0.5	0.5	4.0	2.9	2.0
Opportunity Cost of e-learning	LA	0.4	0.4	0.4	0.3	0.1	0.1	0.1	0.1	0.1	0.1	1.0	0.7	0.5
Opportunity Cost of workshops	NHS	0.5	0.5	0.5	0.5	0.2	0.2	0.2	0.2	0.2	0.1	1.2	0.9	0.6
Opportunity Cost of workshops	LA	0.1	0.1	0.1	0.1	0.0	0.0	0.0	0.0	0.0	0.0	0.3	0.2	0.2
Opportunity Cost of Joint Commissioners	LA	2.9	2.8	2.7	2.6	2.5	2.5	2.4	2.3	2.2	2.1	17.8	12.6	9.0
Opportunity Cost of Lead professional	LA	3.6	3.5	3.4	3.3	3.2	3.0	2.9	2.8	2.7	2.7	22.1	15.6	11.1
Cost of assessment	LA	5.0	1.9	1.9	1.8	1.8	1.7	1.6	1.6	1.5	1.5	12.3	8.7	6.2
Cost of services	LA	4.4	6.0	7.4	8.8	10.0	11.2	12.2	13.2	14.1	14.9	180.6	204.6	199.3
Total		18.8	16.9	18.0	19.0	18.4	19.3	20.1	20.8	21.4	22.0	239.4	246.3	228.9
Total excluding one-off costs		18.8	16.9	18.0	19.0	18.4	19.3	20.1	20.8	21.4	22.0	239.4	246.3	228.9

² Figures may not add up due to rounding

Online Toolkit

The autism toolkit mainly relates to the costs of setting up an autism gateway. The toolkit is being made available to support diagnosis and needs assessment and it is anticipated that this will improve access to diagnosis for all adults with autism.

The Department of Health has commissioned the development of a new online toolkit and information about autism for those working in the health and social care sectors. These will provide an instantly accessible resource for professionals and practitioners to refresh their knowledge and improve their ability to understand and respond appropriately to people with autism. The toolkit is being made available to support diagnosis and needs assessment and it is anticipated that this will improve access to diagnosis for all adults with autism.

The end goal is that NHS practitioners will be able to identify potential signs of autism, so they can refer for clinical diagnosis if necessary, but more importantly so they can understand how to adapt their behaviour and particularly their communication when a patient either has been diagnosed with autism or displays these signs.

The initial set-up, including hosting and 2-3 days a year is estimated to be £5000. Design cost to the is £600. Video/ e-module costs are estimated to be £0.

The opportunity costs associated with the toolkit are negligible. Excluding opportunity costs, there is a one-off cost of around £6,000.

Training

More specific training should be considered, both for those entering the profession and those already working.

Improving autism awareness training for all frontline public service staff

Training managers within local authorities and NHS bodies are responsible for ensuring the delivery of autism awareness training.

NHS bodies and social services should consider what autism awareness training is made available to all staff working in health and social care and how this can be prioritised.

For this training to have maximum impact on identification of autism, it should focus on helping staff identify potential signs of autism and giving them an insight into how to make reasonable adjustments in their behaviour and communication for people who have a diagnosis of autism or who display these signs.

Developing specialist training for staff in health and social care

Training managers within the local authority or NHS body are responsible for ensuring the delivery of autism awareness training.

The immediate aims of this training would be to develop effective training modules and approaches, which will lead not only to improved knowledge and understanding but also to changing the behaviour and attitudes of health and social care staff.

In social care, the Strategy recommends that autism awareness is an essential component of the training given to staff carrying out community care assessments, and all local authorities are encouraged to ensure that their staff have had such training.

There should also be more advanced training for those wishing to follow career pathways that will focus on working with adults with autism – such as becoming personal assistants, occupational therapists or residential care workers.

Local authorities are encouraged to ensure that staff carrying out an assessment have had appropriate autism awareness training.

The cost of training includes the full development of a standard e-learning module including writing the content, instructional design and course build will typically range between £18,000 and £28,000 (£30,000 in 2011/12 prices), depending on the length and complexity of the module.

The costs of training GPs is dependent on the number of GPs who wish to undertake training. It is estimated in research carried out by MedeConnect in 2008 (on behalf of the NAO) that 80% of GPs would like more training or guidance on autism-related issues (based on a sample of 1000 GPs across England). This suggests that, of the 37,213 GPs in England (in 2008, source: NHS information centre – NHS staff 1998-2008 overview), 29,760 would like to undergo this autism-specific training process.

Other healthcare professionals that potentially would undertake the training scheme are community nurse specialists and speech and language therapists. There are 49,113 NHS HCHS qualified psychiatry nurses in England (NHS information centre, 2008) and it is estimated that there are 9,660 speech and language therapists in England (based on 11,500 speech and language therapists in the UK, source: Royal College of Speech and Language Therapists).

Similarly, it has been assumed that around 50,000 social care workers are likely to undertake the training as well.

The costs are also dependent on whether the NHS pays locums, and how long the training takes. We have assumed no locum costs for GPs in this analysis as GPs can do the training as part of their existing training. The opportunity cost based on an hour of e-module training for the GPs trained is around £4.8m (2008/9 prices). This opportunity cost is based on the PSSRU estimate of £2.70 per minute of GP's time (including an allowance for direct practice staff costs but not initial qualifications costs) across the 29,760 GPs in England that have expressed interest in training.

The opportunity cost of training the other healthcare professionals is £1.4 million for NHS HCHS qualified psychiatry nurses (based on the PSSRU 2009 estimate of £29 per hour, not including an allowance for initial qualifications costs) and £0.2 million for speech and language therapists (based on the PSSRU 2009 estimate of £23 per hour, not including an initial allowance for initial qualifications costs).

Similarly, the opportunity cost of training these professionals is around £1.5m (based on the PSSRU 2009 estimate of £29 per hour).

In total, the opportunity cost of training these health and social care professionals is around £7.9m (£8.4m in 2011/12 prices). We have assumed that the training will take place in four years which implies a cost of around £2.1m per year. 36% of this cost falls under LAs and the rest under the NHS.

After the four years of providing training to the stock of healthcare professionals, training will be provided to new professionals (flow). We calculated the number of new professionals in each year using the following information:

GPs-10.2% information from GP Bulletin

Speech Therapists-10.4% NHS Workforce Turnover Statistics

Psychiatric Nurses-7.5% NHS Workforce Statistics

Social Care Workers-11% Skills for care report, 2010 (information for domiciliary care 12.7% day care 3%)

Additionally, 10% of these health and social care professionals will require further more detailed training on autism awareness and may therefore attend a workshop. Again, we have assumed no locum costs for GPs.

It is for each locality to decide how to provide appropriate training but if we assume that workshops are one way forward and that these would last approximately 3 hours and be run by an advanced nurse practitioner, costing £36 per hour (PSSRU 2009 estimate), and have approximately 10 attendees we can estimate that if 1090 workshops are needed over a 4 year period, these would cost around £37,000 in 2008/9 prices (£39,000 in 2011/12 prices). Around 36% of this expenditure falls under LA and the rest under the NHS.

The opportunity cost of the additional training could be around £2.4million in total (£2.5m in 2011/12 prices) or around £630,000 per year for a 4-year period. Around 36% of this expenditure falls under LA and the rest under the NHS. Again, we have assumed that after the four year period, the workshops will be provided to 10% of new professionals using the above mentioned assumptions regarding joining the health and social care workforce.

We have assumed that all of the above mentioned health and social care professionals will undertake the training which may be an overestimate.

Joint Commissioners

As part of the broader aim of enabling local partners to plan and develop appropriate services for adults with autism, the Strategy outlines plans for Joint Commissioners. Joint Commissioners will increase consistency of service availability in each local area, drawing clear lines of responsibility around services for adults with autism.

Joint Commissioners will act as the lead for the development of services for adults with autism in their local area, working in close collaboration with stakeholders to ensure personalisation is addressing the needs of adults with autism.

As set out in existing best practice guidance, it is recommended that Directors of Adult Social Services in every local authority ensures there is a joint commissioner/senior manager who has in his/her portfolio a clear commissioning responsibility for adults with autism. This guidance has not been sufficiently prioritised by many local authorities; mandatory guidance under the requirements of the LASS 1970 will ensure that all local authorities address this issue.

It is assumed that the joint commissioners are directly responsible to a local DASS. Accordingly, the costs are based on an average salary of £50,000. Since they are projected to spend 25% of their time on autism related issues, their inputted cost for this function is £12,500 (plus an additional 45% cost for oncosts and overheads, equivalent to £5,625). If this was rolled out nationally, this would have cost implications of £2,755,000 (£2.9m per year in 2011/12 prices) across 152 local authorities.

These costs are projected to be opportunity costs unless councils increase their total management staff. These opportunity costs are expected to be incurred by local authorities.

Lead Professionals

While we recognise that specialist diagnostic services have proved a highly effective way of making diagnosis more accessible in many areas, it is not expected that a diagnostic team or service will be located in all areas. Instead, the most important step for now is that a diagnostic service should be easily accessible for all areas.

To accelerate this, the strategy recommends that "local areas appoint a lead professional to develop diagnostic and assessment services for adults with autism". This does not require an additional member of staff, but ensuring that someone is allocated responsibility for the task.

Each local area (the local authority and Local Strategic Partnership) should consider appointing a lead professional to develop diagnostic and assessment services for adults with autism in their area.

We assume that the person appointed will spend 25% of their time on autism related issues and that this role will be performed by an advanced nurse practitioner in two thirds of the authorities and by a consultant psychiatrist in a third. The cost of this function (including an additional 45% cost for oncosts and overheads) is £12,300 for an advanced nurse practitioner and £42,600 for a consultant psychiatrist. The total cost in 2011/12 prices is around £3.6m per year.

These costs are projected to be opportunity costs unless councils increase their total management staff. These opportunity costs are expected to be incurred by local authorities.

Diagnosis and Assessment

The Strategy proposes the development of a clear, consistent pathway for diagnosis of autism. The aim is to increase capacity around diagnosis so that in every area of the country people have easier access to diagnosis if they want it.

The Strategy highlights the importance of diagnosis leading to a person-centred assessment of need. Such an assessment, carried out by trained practitioners and taking account of the communication needs of adults with autism, will be the key to unlocking care services and providing a comprehensive view of the person's condition and how it affects them.

The diagnosis of autism should also be recognised as a catalyst for a carer's assessment.

Under the NHS and Community Care Act 1990, local authorities have a duty to carry out an assessment of needs if the adult diagnosed asks for one.

When an adult is diagnosed with autism, healthcare services should inform the relevant local authority adult services department promptly to ensure that a community care assessment can be carried out within a reasonable time period

The PSSRU's publication 'Unit costs of Health and Social Care 2009' provides details on the cost per hour of relevant diagnostic services. All costs are the relevant costs tabulated per hour, not including an allowance for qualification costs.

These cost estimates assume a specified structure to the diagnostic process. Autism diagnosis is not a rigid, specified procedure but we base our cost estimates on a representative assessment undertaken, with information given from Nottingham City Asperger Service, part of Nottinghamshire health care PCT.

This consists of:

Procedure	Amount of time	Cost of session
Autism diagnostic interview (with parent/ carer), undertaken by a community nurse specialist based on PSSRU estimate of £74 per hour of client contact (not including an allowance for qualification costs)	5 hours	£370
Autism diagnostic observation schedule undertaken by a community nurse specialist based on PSSRU estimate of £74 per hour of client contact (not including an allowance for qualification costs)	2 hours	£148
Speech and language assessment and occupational therapy for activities of daily living undertaken by a community speech and language specialist based on PSSRU estimate of £38 per hour of client contact (not including an allowance for qualification costs)	3 hours	£114
Report and feedback to person undertaken by a community nurse specialist based on PSSRU estimate of £74 per hour of client contact (not including an allowance for qualification costs)	5 hours	£370
TOTAL COST	15 hours	£1002

Population statistics are based on 2009 ONS estimates and working age population statistics are based on the categories 16-64, 65-84 and 85+, which we take as an approximation to the working age population. Incidence rates are the same as those used in the publication by Martin Knapp, Renee Romeo and Jennifer Beecham, 'The Economic cost of autism in the UK' .

These cost evaluations use data from the ONS on population estimates and age breakdowns in England as a starting basis. Population estimates and our assumptions are outlined below. These cost estimates assume that 55% of those adults with autism also have a learning disability, while 45% of those adults with an autism have no learning disability. These assumptions are the same as outlined in the publication, the 'Economic Cost of Autism in the UK' by Knapp, Romeo and Beecham (2009).

These cost estimates assume that those adults that have autism that also have a learning disability (227,777), have already been diagnosed. These estimates suggest there are 186,363 individuals in England that have autism that do not have a learning disability. The suggested target group for this Autism strategy is assumed as 50% of those adults that have autism and that do not have an learning disability. Therefore, the target group of this strategy consists of 93,182 individuals (around 25% of all adults with autism).

These figures are illustrative and will be revised when information from the forthcoming prevalence study is available. We have used as the basis for these calculations an estimate of adults with autism without an learning disability as they are more likely to be the group that currently slip through the net and do not

receive any services. This does not mean that there are currently no adults with autism with learning disability who do not slip through the net.

	Percentage	Population figures (million)
Population of England		51.45
16-64	63.5%	32.67
65-84	15%	7.72
85+	2%	1.03
16+ total	80.5%	41.42
Adult autism prevalence	1%	0.41
This consists of:		
Adults with a learning disability	55%	0.23
Adults without a learning disability	45%	0.19
Target group	50% of adults without learning disability	0.09

It is assumed that in the first year since the introduction of the strategy, 5% of our target group (4,659) comes forward for assessment. It is assumed that 2% of the target group comes forward annually for assessment thereafter. These figures are illustrative. We have assumed 1% mortality rate for the stock. This implies that it will take 40 years for the stock to be assessed.

The cost of diagnosis is outlined above, as an average of £1,002 per diagnosis (£1,063 in 2011/12 prices).

In regard to a diagnosis of autism to be a catalyst for a carer's assessment, it is assumed that the ratio of carers to adults with autism is 1:4. This means that each year, 25% of new diagnoses will be accompanied by a carer assessment. This is assumed to take 2 hours to complete by a community nurse specialist. The cost of a carer's assessment is £58 in 2008/9 prices (£62 in 2011/12 prices).

The following table shows the number of assessments for adults with autism and their carers with the costs in 2011/12 prices for a forty-year period.

	Y0	Y1	Y2	Y3	Y4	Y5	Y6	Y7	Y8	Y9	Y10- Y19	Y20- Y29	Y30- Y39
number of adults with Autism assessed ('1000)	4.7	1.9	1.9	1.9	1.9	1.9	1.9	1.9	1.9	1.9	18.6	18.6	18.6
number of carers assessed ('1000)	1.2	0.5	0.5	0.5	0.5	0.5	0.5	0.5	0.5	0.5	4.7	4.7	4.7
cost of assessment (discounted)- £m	5.0	1.9	1.9	1.8	1.8	1.7	1.6	1.6	1.5	1.5	12.3	8.7	6.2

Development of services

The Strategy commits to building capacity and capability at local level to enable local partners to develop relevant services for adults with autism to meet identified needs and priorities.

To achieve this, the strategy makes it clear that each local area should "develop its own commissioning plan around services for adults with autism that reflects the output of the JSNA and all other relevant data around prevalence." The key here is that this must reflect local needs.

Specialist services can be of real value in giving adults with autism the support they need. There are many good examples of specialist services being developed to reflect local needs, but no particular model has become common practice across the NHS and social care and there is at present no robust evidence to suggest that one model is more cost-effective, or delivers better outcomes, than the others. To enable local partners to develop relevant services in every area, the Department of Health will work

with partners to identify best practice and effective service models and promote these to health and social care bodies.

In relation to access to mainstream services, while it will remain up to individual organisations to decide on the adjustments that they can make, potential areas could include:

- taking account of hypersensitivities and providing quiet or lower-light areas
- scheduling appointments at less busy times, allocating extra time to adults with autism and being flexible about communication methods (i.e. less reliance on telephone-based services)
- ensuring essential documents and forms are available in accessible formats – in particular, easy read and formats that take account of sensory issues in their choice of colours, and
- offering opportunities for adults with autism to visit settings in advance to familiarise themselves with what to expect.

It will also need to be recognised that those carers who come forward as a result of a diagnosis of those who they are providing care for will be eligible for assessment of need for support.

The costs of adults with autism are taken from the estimations by Knapp, Romeo and Beecham (2009). It is assumed that of those that come forward for assessment, one-third will become eligible for greater public service provision.

The total number of people newly eligible for extra public service provision at the end of each year is based on the assumption of a mortality rate of 1% of the existing group of newly eligible adults autism. Therefore the total number of adults with autism eligible for extra public service provision as a result of the autism strategy increases over a 10 year period.

It is assumed that the increased use of public services consists solely of increased use of day services, which costs on average £2,226 (£2362 in 2011/12 prices)-this maybe an underestimate as there will be some adults with autism who may need a higher level of service provision. In the first year, this has an annual cost of £1.6 million. Since the total number of adults with autism newly eligible for public service provision as a result of the autism strategy, rises over time, so will the costs.

It is also assumed of those carers that come forward for assessment; one-third will become eligible for 'short breaks'. The cumulative number of carers eligible for 'short breaks', as a result of the Autism Strategy Document is outlined in the table below. These cost estimates have assumed that 'short breaks' consist of an annual two week stay in group homes for people with learning disabilities, priced at £919 per resident week (based on PSSRU 2009 estimates). We have assumed to receive two weeks of respite care (£1951 in 2011/12 prices).

It is assumed that the extra cost of 'short breaks' or respite care is funded by local authorities.

The following table shows the number of adults with autism and their carers in receipt of services at 2011/12 prices.

	Y0	Y1	Y2	Y3	Y4	Y5	Y6	Y7	Y8	Y9	Y10- Y19	Y20- Y29	Y30- Y39
number of adults with Autism in receipt of services in each year ('1000)	1.6	2.2	2.8	3.4	4.0	4.7	5.3	5.9	6.5	7.1	105.6	167.7	229.8
number of carers in receipt of services in each year ('1000)	4.7	1.9	1.9	1.9	1.9	1.9	1.9	1.9	1.9	1.9	26.4	41.9	57.5
cost of services (discounted)-£m	4.4	6.0	7.4	8.8	10.0	11.2	12.2	13.2	14.1	14.9	180.6	204.6	199.3

8. KEY ASSUMPTIONS/SENSITIVITIES/RISKS

In relation to supporting local planning and leadership, the statutory guidance refers to the suggestion in the autism strategy that “local partners may also want to consider establishing a local autism partnership board that brings together different organisations, services and stakeholders locally and sets a clear direction for improved services.”

In some areas, existing structures may fulfil the same purpose – such as Learning Disability Partnership Boards and Mental Health Local Implementation Teams. It has been assumed that in the main that this is what will occur.

The statutory guidance advises that local authorities, NHS bodies and NHS Foundation Trusts should develop local commissioning plans for services for adults with autism, and review them annually. In future, this activity could be led by the local Health and Wellbeing Board under its proposed remit to lead the JSNA and support joint commissioning. Any such plans should be based on effective needs analysis (such as the JSNA) underpinned by good information about adults with autism in the area.

It is assumed that these plans do not necessarily require new information to be collected with associated resource implications. For example, it will be possible to use the national prevalence study DH has commissioned to make local estimates of need.

Many of the costs depend on a variety of central assumptions, outlined above. Four of the proposals from this autism strategy, toolkit, training, lead professionals and joint commissioners have only small risks associated with cost escalation. As a number of figures are based on assumptions this could have implications for the total cost figure, with risks relating to its escalation.

The scale of costs relating to increased assessment and increased use of public services is purely illustrative given uncertainties regarding those coming forward for assessment. The risks to costs per adult with autism are low but a higher risk is attached to the numbers coming forward. We have employed sensitivity analysis to estimate a range of costs relating to assessment and use of public services, and made assumptions about where the numbers and costs are likely to lie.

The risks to this element of the costs are high; there is a high probability that a different figure from 5% of the target group that come forward for diagnosis and a high probability that a different figure from 33% of those who claim extra public service provision, in both cases, the risks lie mainly on the upside.

9. SPECIFIC IMPACT TESTS

Health and well-being Impact Assessment

As the main impact assessment above concerns the health and well-being of adults with autism and their family carers it has been decided not to undertake a specific health and well-being impact assessment.

Equality Impact Assessment

Attached at Annex 2.

Annexes

Annex 1 should be used to set out the Post Implementation Review Plan as detailed below. Further annexes may be added where the Specific Impact Tests yield information relevant to an overall understanding of policy options.

Annex 1: Post Implementation Review (PIR) Plan

A PIR should be undertaken, usually three to five years after implementation of the policy, but exceptionally a longer period may be more appropriate. A PIR should examine the extent to which the implemented regulations have achieved their objectives, assess their costs and benefits and identify whether they are having any unintended consequences. Please set out the PIR Plan as detailed below. If there is no plan to do a PIR please provide reasons below.

<p>Basis of the review: [The basis of the review could be statutory (forming part of the legislation), it could be to review existing policy or there could be a political commitment to review];</p> <p>The Secretary of State has a duty under the Autism Act 2009 to keep the Strategy and guidance under review and publish revised Strategy and guidance if deemed necessary.</p> <p>Impact of all actions to come out of the Strategy and guidance will be assessed– as well as the other steps already taken to transform services for adults with autism in England and Wales – as part of the formal review, in 2013. Arrangements for the review of the Strategy and statutory guidance are currently being developed and will be communicated following publication of the statutory guidance.</p>
<p>Review objective: [Is it intended as a proportionate check that regulation is operating as expected to tackle the problem of concern?; or as a wider exploration of the policy approach taken?; or as a link from policy objective to outcome?]</p>
<p>Review approach and rationale: [e.g. describe here the review approach (in-depth evaluation, scope review of monitoring data, scan of stakeholder views, etc.) and the rationale that made choosing such an approach]</p>
<p>Baseline: [The current (baseline) position against which the change introduced by the legislation can be measured]</p>
<p>Success criteria: [Criteria showing achievement of the policy objectives as set out in the final impact assessment; criteria for modifying or replacing the policy if it does not achieve its objectives]</p>
<p>Monitoring information arrangements: [Provide further details of the planned/existing arrangements in place that will allow a systematic collection systematic collection of monitoring information for future policy review]</p>
<p>Reasons for not planning a PIR: [If there is no plan to do a PIR please provide reasons here]</p>

Add annexes here.

Implementing “Fulfilling and rewarding lives”

- Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy

Equality Impact Assessment

1. INTRODUCTION

This Equality Impact Assessment (EqIA) considers the possible impact of the statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy, on people according to the equality strands of: age, disability, race, religion and beliefs, gender, sexual orientation, pregnancy and maternity, marriage and civil partnership, and gender reassignment.

It aims to assess whether the statutory guidance is likely to have an adverse effect on any of these groups, and whether their human rights are being respected and protected. It highlights where evidence suggests that government and its partners need to ensure that as further policies are developed they promote equality of opportunity.

The autism strategy and statutory guidance are grounded firmly within an equality and human rights approach, and the valuing of the principles of fairness, respect, equality, dignity and autonomy. It is based on the fundamental principle that adults with autism have the same rights as everyone else, and that they should be able to access services and participate in society on an equal basis.

Autism Strategy

Despite the significant strides made over the last decade to increase equality across the UK, adults with autism remain socially and economically excluded.

Adults with autism, and their families, continue to face many barriers in their everyday lives and in accessing the services and support that they need, including:

- their condition being overlooked or misunderstood by professionals and by society,
- difficulties in accessing health and social care services, including transport and housing
- difficulty in gaining long-term, meaningful employment.

In response to increasing evidence of exclusion, detailed in a series of important and telling reports, the Government set out its commitment in the Autism Strategy *Fulfilling and Rewarding Lives* to reduce inequality and ensure adults with autism are able to participate fully in society.

Fulfilling and Rewarding Lives sets out a roadmap towards a society where adults with autism are treated as individuals, like anyone else, and where their needs are recognised and met through mainstream services wherever possible. At the same time, it adopts a practical approach, that reflects the responsibilities that frontline staff already carry. The Strategy recognises the breadth of existing policy and programmes that *should* deliver the support that adults with autism need. Instead of adding to these programmes, many of which are relatively new and have yet to bed down, and adding to the burdens of frontline staff, the Strategy focuses on how to make these existing policies work better for adults with autism.

Statutory guidance for local authorities and NHS organisations

The Autism Act 2009 requires the development by 1 April 2010 of “a strategy for meeting the needs of adults in England with autistic spectrum conditions by improving the provision of relevant services to such adults by local authorities, NHS bodies and NHS foundation trusts.”

Guidance for local authorities and NHS organisations to support implementation of the autism strategy will be issued under section 2 of the Autism Act 2009. As set out in section 3 of the Autism Act 2009, it is to be treated as though it were guidance issued under section 7 of the Local Authority Social Service Act 1970 (LASS Act). This means that local authorities must “follow the path charted by the guidance, with liberty to deviate from it where the authority judges on admissible grounds that there is good reason to do so, but without freedom to take a substantially different course.”

The Autism Act lays out that for the purposes of the autism strategy, section 7 of the LASS Act also applies to NHS bodies as defined.

The Autism Act 2009 requires the Government to consult on and publish mandatory guidance for health and social care to support the strategy's delivery no later than 31 December 2010.

The Autism Act required that guidance covers the following:

- the provision of relevant services for the purpose of diagnosing autistic spectrum conditions in adults;
- the identification of adults with such conditions;
- the assessment of the needs of adults with such conditions for relevant services;
- planning in relation to the provision of relevant services to persons with autistic spectrum conditions as they move from being children to adults;
- other planning in relation to the provision of relevant services to adults with autistic spectrum conditions;
- the training of staff who provide relevant services to adults with such conditions;
- local arrangements for leadership in relation to the provision of relevant services to adults with such conditions.

However, there is no requirement under the Act that these seven areas are covered separately.

Therefore, in recognition of the fact that there are important links between some of these areas, this guidance is structured as follows:

- A. Training of staff who provide services to adults with autism
- B. Identification and diagnosis of autism in adults, leading to assessment of needs for relevant services
- C. Planning in relation to the provision of services to people with autism as they move from being children to adults
- D. Local planning and leadership in relation to the provision of services for adults with autism.

This structure helps clarify the links between these areas and simplifies the guidance. It also ensures the guidance is more clearly focused on the outcomes we seek.

Statutory guidance areas of focus

The following are the areas of focus from the statutory guidance.

A. Training of staff who provide services to adults with autism

- 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. In line with the principles set out in *Fulfilling and Rewarding Lives*, as a minimum autism awareness training should be included within general equality and diversity training programmes³.
- The core aims of this training are that staff are able to identify potential signs of autism and understand how to make reasonable adjustments in their behaviour, communication and services for people who have a diagnosis of autism or who display these characteristics.
- Those staff who are most likely to have contact with adults with autism are the priority groups for training.
- In addition to general autism awareness training for staff, local areas should develop or provide specialist training for those in key roles that have a direct impact on access to

³ *Fulfilling and Rewarding Lives*, paragraph 1.26

services for adults with autism – such as GPs⁴, community care assessors and commissioners/service planners – and those whose career pathways focus on working with adults with autism, such as personal assistants, occupational therapists or residential care workers. The end goal of this specialist training is that, within each area, there are some staff who have clear expertise in autism.

B. Identification and diagnosis of autism in adults, leading to assessment of needs for relevant services

From identification to diagnosis

- As set out in section A above, it is important that staff across health and social care receive autism awareness training so that they are better able to identify potential signs of autism. The aim of this training is that staff can:
 - A. inform the person who may have autism, or their families or carers, about the availability of diagnosis, and direct them appropriately if they want to access diagnosis – for example, explaining how they can get formally referred for diagnosis
 - B. make reasonable adjustments to the way they provide services to the person who may have autism.
- Each area should put in place a clear pathway for diagnosis of autism, from initial referral through to assessment of needs. An important starting point will be to review the current pathway to diagnosis in their area or organisation. Where there is an effective pathway locally, which has the support of clinicians and adults with autism, their families and carers, this should form the foundation of any further changes.
- The NICE clinical guideline for adults with autism is scheduled to be published in July 2012. In order to be ready for the guidance, NHS bodies and NHS Foundation Trusts that commission or provide diagnostic and assessment services need to review existing best practice⁵ now with a view to establishing how it can be adopted in their area or organisation. Once the NICE clinical guideline is published, NHS bodies and NHS Foundation Trusts that commission or provide diagnostic and assessment services should review their diagnostic processes and services against NICE's best practice guidance. The aim of this is to make the diagnostic process more accessible and consistent.
- It is important that all relevant local organisations such as social care teams understand what the pathway to diagnosis is.

From diagnosis to assessment of needs

- Though the strategy introduces no new requirements in terms of assessment, it is vital that local authorities fulfil their duties under the 1990 Act by ensuring that adults diagnosed with autism who may have community care needs are offered an assessment. To enable local authorities to fulfil

⁴ According to the 2009 National Audit Office report *Supporting people with autism through adulthood* “eighty per cent of GPs feel they need additional guidance and training to manage patients with autism more effectively.” (p.19 para 2.3)

⁵ See in particular *Services for adults with autistic spectrum conditions (ASC): Good practice advice for primary care trust and local authority commissioners* (www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_097418) and good practice examples cited in *Fulfilling and Rewarding Lives*

these duties, local authorities, NHS bodies and NHS Foundation Trusts should take the following steps:

- A. When an adult is diagnosed with autism, the NHS body or NHS Foundation Trust providing healthcare services to the adult informs the relevant local authority adult services department promptly to ensure that a community care assessment can be carried out within a reasonable time period if the individual wants such an assessment and with the individual's consent.
 - B. The social services department then contacts the adult with autism – and any registered carers – to inform them of their entitlement to an assessment and inform carers of the right to a carer's assessment.
 - C. In addition, healthcare professionals who make a diagnosis of autism inform the adult diagnosed, and/or their carers, that they also have the right to request such an assessment. This will help ensure that if adults diagnosed with autism are not offered an assessment by the local authority following diagnosis within a reasonable time period, they can still access one.
- All assessments should be conducted in line with the processes and principles adopted in the development of *Working to Put People First: The Strategy for the Adult Social Care Workforce in England*.
 - In line with the principles of *Fair Access to Care Services*, assessment of needs should be carried out by a professional who has a good knowledge of autism, and reasonable adjustments made to the assessment process to enable the adult with autism to take part fully.
 - If an adult who has previously received an assessment of need for care services is subsequently diagnosed as having autism, this is a potential reason for reassessment. If an adult who has previously been refused an assessment of need is subsequently diagnosed as having autism, this is a reason for assessment.
 - Assessment of eligible needs for services should not be influenced by availability of services: for example, if the assessing professional identifies that the adult with autism would benefit from an advocate, the report should reflect that whether or not advocacy services are available. This will not only help the adult with autism access the right services in the future, or benefit from relevant support when in employment or education, but also will feed into the overall picture of the needs of adults with autism in the area, and local JSNA.

Responsibilities

- Each local authority should appoint a lead professional to develop diagnostic and assessment services for adults with autism in their area. This should be done in conjunction with the Local Strategic Partnership.
- The Director of Adult Services is responsible for ensuring that the correct processes are in place within the local area for:
 - A. conducting assessments of needs
 - B. the prompt sharing of information between diagnostic services and adult services about adults diagnosed
 - C. timely formal notification of the entitlement to an assessment of needs and, where relevant, a carer's assessment.

C. Planning in relation to the provision of services to people with autism as they move from being children to adults

- Local authorities need to comply with their existing legal obligations under the statutory guidance around transition planning in relation to their social services responsibilities for children and young people set out in the *Special Educational Needs Code of Practice*⁶. Guidance, including legislative requirements and case study examples, are set out in *A transition guide for all services*⁷.
- Professionals working with a young person with autism approaching transition, including CAMHS professionals, SENCOs and social workers should inform the parent and young person of their right to a community care assessment and inform carers of the right to a carer's assessment.
- Professionals working with a child with autism approaching transition should inform social services that this individual is approaching adulthood and may need community care assessment. The social services department should then formally contact the young person with autism, and their family, before the young person reaches to adulthood, to invite them to receive a community care assessment.
- NHS bodies and NHS Foundation Trusts should ensure that protocols are in place in every local area for the transition of clinical mental health care for children with autism in receipt of CAMHS. Where individuals do not fulfil referral criteria for adult mental health teams, measures must be put in place to ensure that those individuals can receive support elsewhere, through adult social care or from signposting on to other non-statutory services. Commissioners must be informed of gaps in services in these instances to support future planning of need.
- The Director of Adult Services is responsible for ensuring that the local area follows its statutory duties around transition planning and that the local area meets at least minimum standards in transition planning.

These policies apply to young people with autism. They are all existing responsibilities.

D. Local planning and leadership in relation to the provision of services for adults with autism

- Local authorities should allocate responsibility to 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.
- NHS bodies and NHS Foundation Trusts should develop local commissioning plans for services for adults with autism, and review them annually. Any such plans should be based on effective needs analysis underpinned by good information about adults with autism in the area.
- The commissioning of services should take account of the need for appropriate services such as care and support, travel training, etc.
- To develop such plans, it will typically be necessary to gather information locally about:
 - The number of adults with autism in the area
 - The range of need for support to live independently

⁶ [Special Educational Needs Code of Practice \(reference DfES 51/2001\)](#)

⁷ [A transition guide for all services \(DCSF & DH reference 00776-2007DOM-EN\)](#)

- The age profile of people with autism in the area – including those approaching 65 or above working age and the number of children approaching adulthood, to enable local partners to predict how need and numbers will change over time.
- This does not necessarily require new information to be collected with associated resource implications. For example, it will be possible to use the national prevalence study DH has commissioned to make local estimates of need.⁸ Also, under the disability equality duty, local authorities are required to monitor the impact of their policies and to develop policies having regard to the impact of them on disabled people. They are under a duty in carrying out their functions to have due regard to promote equality of opportunity. The ability to fulfil that duty depends on gathering information about adults with disabilities in the area. This means that local authorities should already by gathering some or all of the information set out above as part of fulfilling the equality duty.
- In addition, it will also be valuable for local authorities to collect information about the numbers of adults with autism who are:
 - in employment in the area
 - likely to need employment support in order to work
 - placed in the area (and funded by) other local authorities
 - placed out of area by local authorities
 - in hospital or living in other NHS-funded accommodation
 - resettled from long-stay beds or NHS residential campuses to community provision
 - living at home on their own, or with family members, and not receiving health or social care services, or
 - living with older family carers.
- It will also be useful to gather information about the ethnicity, gender, religion or belief and sexual orientation of adults with autism so that local authorities, NHS bodies and NHS Foundation Trusts can understand the numbers of people from different backgrounds with autism.
- In developing these plans, local authorities, NHS bodies and NHS Foundation Trusts should consider the role of local community and volunteer groups in delivering services to meet the needs of adults with autism.
- Local commissioning plans should set out how the local authority will ensure that adults with autism are able to access personal budgets and benefit from the personalisation of social care. As part of this, it will be important to consider the practical challenges involved in granting more choice to adults with autism, drawing on the principles set out in the Mental Capacity Act 2005⁹.
- All local authorities, NHS bodies and NHS Foundation Trusts who provide mental health and learning disability services are recommended to review the DH guidance about the adjustments to service delivery to include adults with autism.
- All local authorities, NHS bodies and NHS Foundation Trusts and organisations with whom they have contracted to provide services are expected to take into account the views of adults with

⁸ The Department of Health (DH) is funding a study to explore rates of autism in a representative sample of adults in England. The contract was awarded by the NHS Information Centre on 26 March 2011 to a consortium led by the University of Leicester. The other members of the consortium are the University of Glasgow, Kings College London and the National Centre for Social Research (NatCen). Findings are expected in early 2011. See www.ic.nhs.uk/news-and-events/news/nhs-information-centre-awards-autism-study-contract-to-university-led-consortium

⁹ See www.legislation.gov.uk/ukpga/2005/9/section/1

autism and their families and carers in developing and commissioning services for adults with autism.

- The Director for Adult Social Care in each area is responsible for:
 - developing the area's commissioning plan around services for adults with autism, using the best available information about adults with autism in the area
 - appointing a joint commissioner/senior manager who has in their portfolio a clear commissioning responsibility for adults with autism
 - ensuring that the views of adults with autism and their carers are taken into account in the development of services locally.

Rationale for Government Intervention

Over recent years, it has become increasingly clear that a significant proportion of adults with autism across the whole autistic spectrum, are excluded both socially and economically. The National Audit Office (NAO) report: *Supporting People with Autism through Adulthood* reveals evidence of services not meeting need across the public sector and made recommendations to central and local government to deliver change.

This is not just a health and social care problem. Service-engendered barriers to education, employment and the wider community bring economic disadvantage, social isolation, and mental and physical ill health for adults with autism.

We are beginning to be aware of the scale of people with undiagnosed and therefore untreated autism (particularly those on the higher end of the spectrum) who exhibit particularly challenging behaviour in the community that invariably draws them to the attention of criminal justice services. Lack of understanding of the condition means that problems that might be speedily resolved with appropriate community-based support in some cases result in custodial sentences, at an increased cost to the public purse.

Consultation for the Autism Strategy

A consultation was undertaken during summer 2009 to gather views on the focus and direction of the Autism Strategy. Adults with autism, family carers, professionals and representative organisations were invited to identify the priority areas for change.

A number of consultation events were held to gather feedback on the proposed Strategy, including an event for Black and Minority Ethnic groups run in conjunction with National Voices. These events were attended by adults with autism, carers and family members, and service professionals, and took the form of discussions on the experiences and needs of people with autism as well as possible solutions.

The Department of Health also established an External Reference Group to help develop the Autism Strategy. Membership included adults with autism, parents/carers/supporters, professionals, and representatives from voluntary sector organisations and independent sector providers. The Group identified the five key priorities for action set out in the Autism Strategy consultation document *A Better Future* : Choice and Control, Training, Health, Employment and Social Inclusion.

The response to the consultation identified a lack of understanding of autism across public services, and that too many professionals in every sector are unaware of how autism might affect an individual's life and capabilities. People with autism often experience a lack of understanding of their condition and inflexible services which often make no accommodation for their unique set of needs.

The consultation also highlighted a lack of understanding more broadly in society. Though there were relatively few accounts of deliberate discrimination against those with autism, there were multiple examples of where adults with autism have felt excluded, misunderstood and harassed.

The core themes of the Strategy were chosen to reflect the findings of the consultation, the themes emerging from the External Reference Group and the conclusions of important studies such as the 2009 National Audit Office report.

Consultation for statutory guidance for local authorities and NHS organisations

A consultation was undertaken from July to October 2010 to gather views on the focus and direction of the draft statutory guidance. Adults with autism, family carers, professionals and representative organisations, and health and social care bodies were invited to comment on the draft statutory guidance being consulted on.

Consultation events were held in localities across England to gather feedback on the proposed statutory guidance. As part of these events, equalities and human rights issues relating to the draft guidance were raised to promote discussion and enable the sharing of views on the topics.

Consultation packs were distributed to those organising events, and encouragement was given to invite people from the above groups who may also fit into one of the equalities strands to attend. Among other topics, organisers of the events were encouraged to open up for discussion the issue of how personal perceptions of autism can potentially influence those commissioning and providing services.

A number of consultation workshops were held by the Department of Health to gather feedback on the proposed statutory guidance, including an event for Black and Minority Ethnic groups. These events were attended by adults with autism, carers and family members, and service professionals, and took the form of discussions on the draft statutory guidance.

Key concerns highlighted during the consultation focused on the strength of the language of the document and structure of the guidance in separating diagnosis, identification and assessment of needs into different sections. There were also concerns raised regarding the guidance only referring to health and social care, adults with autism 'falling through the gap' between mental health and learning disability services, and the importance of involving adults with autism at every level in the implementation of the autism strategy and statutory guidance.

2. THE EVIDENCE BASE

Current evidence shows around 400,000 adults in England have autism, (approximately one per cent of the population¹⁰).

The EqIA for the Autism Strategy highlighted the lack of direct formal evidence relevant to adults with autism. Little is known in relation to service models, support strategies, and treatment of people with autism.

To further increase knowledge on the prevalence of autism in adults, the Department of Health is funding a study to explore rates of autism in a representative samples of adults in England and build on the small-scale study which began in 2008 to help identify a suitable way for improving the accuracy of estimating prevalence in the adult population.

The study will report its findings in 2011, and provide important insights not only into the total number of adults with autism, but also where they are on the spectrum.

In addition, the Department of Health, as committed to in *Valuing People Now* (2009), has established a Public Health Observatory (PHO) in relation to people with learning disabilities as well as people with autism. The work of this new PHO will include the collation of existing data on the prevalence of people with autism, what services they access, and the quality of those services.

¹⁰ Knapp et al., *The Economic Consequences of Autism in the UK* (2007).

Summary of key research

Most of the research identified below addresses autism specifically but broader research on Learning Disabilities has been referenced on the basis that approximately half of adults with autism will also have a learning disability.

Age:

- Welsh Assembly research into autism and ageing suggests that the accepted prevalence rate of 1 in 100 holds true for older people. It is thought that there are a large number of older adults with autism. Adults with autism experience the same age-related mental health conditions as the rest of the population. However, even though the service-user may have a co-morbidity of autism and a mental health condition, often only the mental health condition is recognised and the autism left undiagnosed and unsupported.
- *I Exist* (NAS, 2009) suggests that there is a higher prevalence of mental health conditions in people with autism over the age of 40. Furthermore, those aged 65 years and over with autism are likely to either have no support or rely heavily on family members.
- Walker et al (1998) compared the treatment of older and younger people with learning disabilities and found that some care workers made assumptions about older patients and as a result restricted the number of opportunities available to them.
- The medeConnect survey (2008)¹¹ of 1,000 GPs in England to investigate the number of patients in different age groups, looked at ongoing support and examined how confident GPs are that patients in their area with autism are receiving adequate and appropriate care. The survey found that the majority of GPs see between 800 and 3000 older people in a typical six-month period, and on average (estimated) 5 of these service users would have symptoms of autism but no diagnosis. One in six GP's were not sure where they would refer older patients with 'higher functioning' autism. Overall, GP's confidence levels that patients with autism were receiving appropriate and adequate care was found to be low.

Disability:

- The 2006 Disability Rights Commission report on inequalities in physical health concluded, people with a mental illness or learning disability are much more likely *"than other citizens to have significant health risks and major health problems"* ¹²
- The National Audit Office report (2009) recognised the problems of diagnosing autism, particularly in mental health settings. Many people with autism have an increased risk of social exclusion and health problems, particularly a risk of mental illness. This means they only engage with services when their health has deteriorated, to a point of requiring acute interventions.

Ethnicity:

- Two studies into ethnicity and autism provide different conclusions on the prevalence of autism in different ethnic groups, from variable rates to comparable rates (Powell et al, 2000) (Fombonne, 2007).
- Since 2005, the *Count Me In* census has found that admission rates to Learning Disability services were lower than average among South Asian, Other Asian and Chinese groups, and were between two and three times higher than average in the White/Black Caribbean Mixed, Black Caribbean and Other Black groups.
- Tsakanikos (2009) found that black people who had been referred to a mental health service for people with intellectual disabilities were more likely to have autism than other groups. Referrals of ethnic minority groups were more likely to be younger than white referrals and less likely to be in supported residences.
- Goodman and Richards (1995) found autism to be more common in a group of African-Caribbean people than in a predominately-white group of patients.
- Wing (1993) estimated the prevalence of autism in children of Caribbean origin to be 6.3/10,000 compared to 4.4/10,000 for the rest of the population.

¹¹ MedeConnect (2008) *Survey of General Practitioners in England on the subject of Autism, Prepared for the National Audit Office*

¹² Disability Rights Commission (2006), *Equal Treatment Closing the Gap. Health Formal Investigation Report. Summary for Practitioners*

Gender (including transgender):

- The Adult Psychiatric Morbidity Study highlighted prevalence in men of around 1.8% and around 0.2% in women providing an average of 1 in 100 across England¹³.
- Several studies suggest that different levels of prevalence could be due to difference in presentation and diagnosis (Medical Research Council, 2001).
- Hospital Episode Statistics 2008-9 inpatient data with a primary diagnosis of either childhood autism, atypical autism or Asperger's Syndrome show a higher percentage of cases being male.
- For disabled women in general, and for women with learning disabilities, gender roles, self identity and sexual identity may remain ambiguous because of how their lives are constructed by the professionals who come in contact with them (Phillips, 2004).

Religion or Belief:

- Valuing People Now Equality Impact Assessment (DH, 2009) found little attention has been paid in the past to the spiritual needs of people with learning disabilities.
- The Delivering Race Equality in Mental Health (DRE) did not find a specific correlation between mental illness and religion independent of ethnic background. However, the DRE programme does highlight the importance that faith and spirituality can play in how individuals perceive mental health and well-being.

Sexual Orientation:

- Health Scotland (2008) research suggests that the extent to which a learning disability affects a person's level of understanding may mean that they have less opportunity to make and develop relationships, and are less likely to learn about sexual development.
- Stonewall (2007) research found that despite 1 in 15 older people being either lesbian, gay or bisexual, LGB people remain relatively invisible in the health and social care system. Whilst many of the problems facing LGB people are similar for heterosexual people, these challenges are often more acute for LGB people.
- Thompson et al (2001) found that there is a lack of supportive education for sexual identity formation for LGB people who have a developmental disability.

Autism Strategy and Statutory Guidance consultation evidence

The consultations on the adult autism strategy and statutory guidance asked specific questions on equality, discrimination and harassment issues. There were over 100 specific comments relating to these issues. A summary of these comments are found below.

Age:

- There are a large number of older adults who may have undiagnosed autism, or have been diagnosed with having a mental health condition when in fact they don't.
- Autism is often thought of as a childhood condition.
- Many health and social care professionals working with working age and older adults in mainstream services lack awareness and understanding of autism which can lead to inappropriate referrals or services.
- Treatment seems to be focused on children and young people and any available service is targeted towards them. As an adult getting a diagnosis is extremely challenging, and little or no access to services/support/therapy is available.
- Families and carers highlight that there are some adults with autism who are living at home with elderly relatives, placing anxiety on these parties to successfully plan for the future.
- Transition planning needs to also apply to people with autism who are older in age, especially when their primary carers pass away.

¹³ NHS Information Centre (2007), Autistic Spectrum Disorders in adults living in households throughout England: Report from the Adult Psychiatric Morbidity Study

Disability:

- Many respondents stated that they were not taken seriously, or treated as incompetent.
- The DDA and DED are not working for adults with autism, difficulties in communication or literal interpretations were often viewed by professionals as rudeness or aggravating behaviour.
- Adults with a high IQ and autism may present as not having specific needs as they can engage and communicate very well, but often need support for small tasks and organisation.

Ethnicity:

- Cultural definitions of disability and the importance of maintaining a strong presence in the community, especially for older adults in some BME communities, means that deteriorating health conditions are often ignored or put to one side.
- Some ethnic communities put pressure on children to achieve very highly in an academic setting, and learning difficulties are not accepted easily.
- Involvement of independent advocates to support individuals with autism can lead to conflicts between the specific individual and their family, for example if there are pressures of arranged marriage.
- Adults with autism from BME groups may not access services or ask for support because autism may not be recognised in some communities, there is little information about autism in the language spoken in that particular community, or families may want to care for adults with autism in their own communities without the help of outside services.
- BME people with autism may suffer from racial stereotyping.
- In the Asian community there is a lack of knowledge and understanding of Asperger syndrome or autism contributed by the difficulty in understanding information that is only provided in English.
- There is also stigma and denial in Asian communities about people having autism, and community pressure often stops people coming forward.
- Training in the NHS should be mindful of resistance to diagnosis of family members in certain communities, and different cultural aspects in general .
- There are difficulties for some people from certain communities being involved in local autism groups because of the stigma associated with autism.

Gender (including transgender):

- The diagnosis of women with autism appears to be more difficult as a result of them having a greater social awareness; and the description of autism in diagnostic guidelines favouring male diagnosis. There is some evidence that women with autism are more likely to be diagnosed with personality disorders.
- Women with Asperger syndrome are misunderstood and undiagnosed, because they are better at hiding their condition and because every individual experiences the condition differently.
- Women with autism have more difficulty accessing services. It is generally considered that the majority of people with autism are men and services are geared towards them.
- People tend to think of boys and men when they think about who might have autism and may not even be aware that a girl or woman may have the condition – this can even mean a woman cannot get her doctor to refer her for diagnostic testing.
- The consultation provided anecdotal evidence that there are a significant number of transgendered women with Asperger syndrome, and not necessarily transgendered men.
- Some people with Asperger syndrome have transgender issues, which may involve medical treatment. Other people with Asperger syndrome can become fixated with their gender as one of the "causes" of their condition. It is important that is dealt with sensitively.
- Several responses highlighted the isolation that transgendered people can experience within the health and social care system, and the provision of additional services that meet the needs of people e.g. bisexual or transgender people with autism, could prevent the isolation that is likely to occur when people feel misunderstood by society.

Religion or belief:

- Several comments highlighted issues around religion but not autism itself.
- Some people report difficulty getting a hospital appointment on a day that doesn't clash with certain religious days of other faiths and not just the main English faiths.

Sexual Orientation:

- Sexual orientation was an issue raised less than other equality issues. For many however, it was the difficulty with social skills that can lead to sexual orientation issues.
- Homophobic abuse is often used in bullying situations and this can be very confusing for people with autism. Gay people with autism may have their differences attributed to their sexuality. Social skills training may not be able to give appropriate relationship support. There may be problems relating to social gender roles.
- Belief that more people with autism will define themselves as bisexual than the general population, because they may be less constrained by social convention and concerned about what others think and so less likely to say heterosexual. Services need to be aware of this and staff need to be skilled to respond positively.
- There seems to be a lack of specific services for those with autism who are of non-heterosexual orientation. It is hard enough to make and find relationships, but it is harder still if one is a lesbian, gay, bisexual or transsexual with autism. At present there seems to be no groups geared to facilitating encounters for people who are LBG and have autism.
- There is a need for sympathetic/empathetic educators to help build confidence in people looking to form same-sex relationships.

3. CHALLENGES AND OPPORTUNITIES

Under the Disability Discrimination Act (DDA) (1995 & 2005) service providers such as hospitals, GP and dentist surgeries, pharmacies and specialists such as physiotherapists cannot discriminate or provide a poorer quality of service to disabled people because of their disability. Service providers must give due regard to taking steps to take account of disabled persons' impairments, even where that involves treating disabled persons more favourably, and be prepared to provide reasonable adjustments for disabled people to enable them to access services more effectively.

Too often, this aspect of the duty has been overlooked with regards to adults with autism, with the focus mainly on physical and sensory impairment.

All public bodies in England are also required to publish a disability equality scheme, demonstrating how they intend to fulfil their general and specific duties under the DDA. Public bodies should involve disabled people in the development of the scheme, implement the action plan set out in the scheme, and review and revise the scheme every three years.

Autism, as a lifelong disability, is included under the DDA and adjustments should be made as such if necessary. The Autism Strategy and Statutory Guidance reinforces the DDA and subsequent duty, promoting equality for all adults with autism.

Age

The Autism Strategy and draft statutory guidance aim to improve the lives of all adults with autism, regardless of age.

The statutory guidance, does also encompass transition, specifically those individuals with autism who are below 18 and who are involved in the process of transferring from children's to adult services. The statutory process of transition planning for children with special educational needs statements starts from 14 years of age (year 9). It is important that this transition period is effective to ensure that young adults with autism are still being provided with the services they need when they become an adult.

Evidence presented in this assessment suggests that older people with autism may face exclusion due to a lack of diagnosis and adequate support. The strategy and statutory guidance promotes the needs of all adults, of all ages with autism.

Disability

The Autism Strategy and statutory guidance is underpinned by the vision of equality for adults with autism, reiterating the requirement under the Disability Discrimination Act 2005 for services to make reasonable adjustments for disabled adults, including those with autism. The Strategy and statutory guidance seeks to reduce inequalities for adults with autism and improve access to services across the public sector.

The emphasis on inclusion and accessing diagnosis and support, have the potential to have a wider positive impact on adults with autism, including:

- people with autism being more trusting of public services, and being more able to use them,
- less chance of delay in diagnosis and treatment of often minor health conditions,
- people with autism being better able to navigate the benefits system and receive relevant employment advice, and
- reducing difficulties people with autism experience with using public transport, and making it easier for them to use community services and activities.

Ethnicity

The strategy and statutory guidance recognises that adults with autism from BME groups may face difficulty in accessing services. There is anecdotal evidence that many in BME communities do not make use of health and social care services, potentially because of cultural decisions not to access the services or the lack of understandable information on the topic.

Encouraging local authorities to explore how to support volunteer and third sector groups in planning and commissioning services will help promote equality in smaller community groups. Where services are provided, we expect that they will have taken into account the various equalities duties when being commissioned.

It is important that the issues adults with autism face are properly addressed within the context of the personalisation agenda. This is especially the case for those from BME communities.

Gender (Including transgender)

Evidence and research cited in this assessment highlight that autism is more prevalent in males than in females.

Autism is often thought of as a male only condition, which is not the case. Comments on this issue from the consultation highlight the difficulty that women have had in getting a diagnosis/accessing services. The focus on personalisation and access to information should result in a focus on the individual, of which gender is a key part.

Religion or Belief

Improving access to services, and promoting social relationships as well as ensuring that adults with autism have the same rights as everyone else are important goals for the strategy and statutory guidance. In this respect, the strategy and statutory guidance can be seen to be promoting the rights of individuals with autism to practice their own religion or belief.

Sexual Orientation and Gender Reassignment

The Government's vision for transforming the lives of and outcomes for adults with autistic spectrum condition is to ensure that they can live fulfilling and rewarding lives. This includes being able to have relationships and social networks and public services to treat them fairly and as individuals.

Pregnancy and Maternity, and Marriage and Civil Partnership

The ability for people with autism to have relationships that potentially may lead to marriage or civil partnership is included in the Government's goal for people with autism to live fulfilling and rewarding lives, as well as people with autism's right to be treated fairly as individuals when accessing pregnancy and maternity services.

4. NEGATIVE IMPACT

Age

There is little evidence to suggest that the Autism Strategy nor statutory guidance will have a negative impact on different age groups. While the Strategy and statutory guidance do focus on people with autism who are 18 years and over, it also addresses the transition period between child and adult services.

Disability

The Autism Strategy and statutory guidance seek to address the inequality experienced by adults with autism, facing both social and economic exclusion. The Strategy and statutory guidance will address this inequality experienced by all adults on the whole autistic spectrum. It is not expected that the Strategy or statutory guidance will impact negatively on disability equality.

Ethnicity

The lack of information makes it difficult to assess the impact of the Strategy and statutory guidance on adults with autism from BME groups, but the Department will continue to work to improve the information available and work with stakeholders on this issue.

Gender (including transgender)

There is potential that, without effective awareness raising, autism may continue (from the results of the consultation) to be seen as a male-only condition. The Department of Health will investigate further the rates of autism in a representative sample of adults in England.

Religion or Belief

Future work on guidance and good practice will need to take account of the spiritual and religious needs of adults with autism.

Sexual Orientation and Gender Reassignment

Lack of information and data around sexual orientation and gender reassignment is a potential issue which the Department will continue to work to improve.

Pregnancy and Maternity, and Marriage and Civil Partnership

Lack of information and data around pregnancy and maternity issues, and marriage and civil partnerships is also a potential issue which the Department will continue to work to improve.

Bruce Calderwood, Director of Mental Health and Disabilities

1 December 2010

Action plan

- Engagement with key partners:
 - The Department of Health will continue to communicate with key partners and voluntary sector organisations to gain more of an understanding of how equalities duties relate to adults with autism.
 - **Target Date: Ongoing**

- Governance:
 - The Department of Health will ensure the national autism programme board overseeing progress on the Strategy and Statutory Guidance will include in its remit compliance on all equalities duties.
 - **Target Date: Ongoing**

- Awareness raising:
 - The Department of Health will work with professional bodies and the Royal Colleges to develop and deliver effective information and publications related to autism. These will need to take into account specific challenges in regard to various equalities duties.
 - **Target Date: March 2011**

- Evaluating Progress:
 - The Department of Health will take account of all equalities duties when producing advice on evaluating progress against implementation of the Autism Strategy and Statutory Guidance.
 - **Target Date: December 2010**

- Data collection and research:
 - The Department of Health will report the findings from the autism transition study and prevalence study, ensuring that any information relating to the various equalities strands has been taken account of when delivering the Strategy and Statutory Guidance.
 - **Target Date: 2011**